Every Voice Matters

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Introduction

The theme for Lupus Europe Annual Convention 2025 was “Every Voice Matters”. Lupus is a complex and highly heterogeneous condition, and no two experiences of lupus are ever exactly the same. People living with lupus may face very different realities depending on the way their disease presents, the support available around them, the healthcare system they live in, and whether their needs, perspective, and voice are truly heard. Differences in access to diagnosis, treatment, information, support, and understanding can have a profound impact on quality of life and on long-term outcomes.

At the same time, the diversity of lived experience within the lupus community is not only a challenge to recognise, but also an essential source of insight, learning, and progress. Recognising the importance of listening to a wide range of voices, addressing disparities, and valuing diversity, the Convention focused on how much stronger care, collaboration, and solutions can grow when every voice matters.

40 delegates from **20** countries and **11** industry partners joined the Convention.

Please note that the summary below is based on notes taken by the secretariat and reviewed by some Board members. It should not be taken as a complete and literal abstract of the presenters’ work and might contain simplifications or unintended omissions. Slides used by the presenters are available for members; if you are a member and would like a copy of the slides please e-mail secretariat@lupus-europe.org

Opening Session

Jeanette Andersen, Chair of Lupus Europe, welcomed delegates to the Convention and opened the meeting with practical information on the programme for the days ahead. Jeanette introduced the sessions planned across the Convention, including scientific presentations, workshops, the poster tour, the General Assembly, and a number of interactive activities designed to support exchange between national groups. She also highlighted some of the organisational initiatives that Lupus Europe is putting in place to strengthen communication and connection between national delegates, including a WhatsApp group intended to facilitate quick contact, practical questions, and the sharing of activities, campaigns, and ideas across National Members.

Jeanette encouraged delegates to make active use of the opportunity to learn from one another and to share what they are doing in their own countries. She also drew attention to sessions that would showcase achievements from the past year, top-line findings from the Living with Lupus in 2024 survey, and practical tools and resources available to member groups. The Opening Session set the stage for a Convention centred on learning, exchange, and concrete action, while also reinforcing the importance of collaboration between Lupus Europe and its National Members.

The session also introduced the wider spirit of this year's Convention theme, “Every Voice Matters”, which would run through the scientific sessions, workshops, and contributions from around the world. Later in the morning, Jeanette returned briefly to highlight the importance of the Patient Advisory Network (PAN), encouraging National Members to identify people interested in research from within their membership. Jeanette also introduced short video contributions from lupus groups from beyond Europe, aimed at ensuring that perspectives from other parts of the world were also present within the Convention and helping broaden the conversation around equity, access, and lived experience.

What is New in Lupus

by Dr. Maarten Limper

Dr. Maarten Limper, internist, immunologist, and member of the Medical Advisory Board of the NVLE, the Dutch Lupus National Group, opened the programme with a session on what is new in lupus. His presentation combined an overview of recent clinical developments with a broader reflection on inequities in lupus care, linking scientific progress to the Convention theme of “Every Voice Matters”.

Dr. Limper began by explaining that lupus is a highly heterogeneous disease, with no two patients experiencing it in exactly the same way. He guided delegates through some of the immunological background of lupus, including how the immune system can begin reacting to the body’s own cells and tissues, setting off inflammatory pathways that may ultimately affect organs such as the kidneys. While some parts of the presentation were necessarily technical, the focus remained on helping delegates understand why lupus behaves so differently from person to person and why treatment is rarely “one size fits all”.

A significant part of the session focused on lupus nephritis. Dr. Limper explained how inflammation in the kidneys can develop and why early recognition and treatment are so important in preventing long-term damage. He then talked delegates through the most recent changes in lupus nephritis guidelines, highlighting a move towards lower steroid use and more combination or “multi-target” treatment strategies from the outset. He discussed several newer therapies now being used or evaluated in lupus care, including belimumab, voclosporin, and obinutuzumab, and emphasised that while new treatments are not automatically “better” than older ones, having more options is an important step forward.

Dr. Limper also addressed the concept of remission in lupus, noting that this remains an evolving area. He explained that remission is no longer understood simply as the absence of a few symptoms but is increasingly being defined in a more structured and meaningful way, taking into account disease activity, treatment burden, and what is realistically sustainable over time.

Alongside recent treatment developments, the presentation also looked to the future. Dr. Limper briefly touched on emerging approaches such as CAR-T cell therapy, describing these as very promising for some patients with severe disease, while also stressing that much remains to be understood about where such treatments should sit in lupus care. Dr. Limper’s message was one of cautious optimism: there is significant progress happening in lupus, and although many questions remain, the field is moving towards more choice, more precision, and more personalised treatment approaches for patients.

In the second part of the session, Dr. Limper turned to inequities in lupus care. Drawing on his own experience of working in the Caribbean, he reflected on the very different realities patients may face depending on where they live. He described how delays in diagnosis, lack of access to specialists, limited infrastructure, restricted availability of medication, and wider systemic barriers can all lead to poorer outcomes and greater organ damage.

Dr. Limper highlighted the important role of the European Reference Networks, including ERN ReCONNET, in helping reduce inequities across Europe by connecting expertise and supporting more equal access to specialist knowledge. He suggested that this kind of collaborative model could also offer inspiration for wider international cooperation in the future. He also underlined the role patient organisations can play in keeping inequities visible, sharing experiences, and continuing to bring these issues to the attention of policymakers, researchers, industry, and the wider lupus community.

The session offered delegates both a useful overview of current clinical developments and a wider reminder that progress in lupus must also be measured by who is able to benefit from it.

Lupus Europe Celebration of Achievements

The morning continued with the Lupus Europe Celebration of Achievements session, where the Lupus Europe Board reflected on the milestones, growth, and collective progress of the organisation over the past year. In a warm and interactive format, Board members presented key developments across Lupus Europe's work, while beginning to add leaves to a tree representing the organisation's projects, partnerships, and achievements; a living testament to shared success, collaboration, and purpose. However, Lupus Europe is its members. This session therefore continued the following day, when National Members were also invited to share their own achievements and add further leaves to the tree.

The session highlighted the breadth of Lupus Europe's work in patient involvement in research. Jeanette Andersen presented developments in the organisation's Patient Advisory Network (PAN), including active participation in 24 active projects, contributions to advisory boards in industry and academia, training opportunities for PAN members, and the continued strengthening of in-house training capacity in areas such as HTA (Health Technology Assessment). She also reflected on recent training initiatives, including a bespoke mental health first aid course for volunteers and National Members, training on "how to tell your story", and a range of soft-skills trainings for PAN members.

Strong participation in ERN ReCONNET was also highlighted, with Lupus Europe continuing to play a leading role in the ERN ReCONNET SLE Working Group, the patient partnership group, and a wide range of related working groups within the Network. The Board also celebrated progress on the RareERN Path project, which gathered 831 patient stories in 14 languages, greatly exceeding the original target of 200 stories and providing a rich contribution to understanding and improving the lupus patient pathways in Europe. Other achievements included the translation of consultation cards into three languages, strong visibility at the ERN ReCONNET Congress where Alain Cornet won an award for Best Abstract and Poster Presentation, and active participation on the ERN ReCONNET Strategic Board by Jeanette Andersen.

A number of scientific publications and collaborative projects were also presented. These included publications on social determinants of health, the role of patients in rheumatology, and on the communication gap between patients and physicians. The Board also highlighted involvement in projects including the Lupus Brain Fog Severity Scale, LUPUS ALERT, the ENDORSED project, TRM-SLE, and multiple EULAR recommendations and other international initiatives.

The session also celebrated progress in communication, outreach, and visibility. The Board shared that social media growth had exceeded target, with monthly hashtag campaigns on nonpharmacological measures helping maintain momentum across the year. Lupus100 had reached 1.3 million views and was now available in 19 languages, while LupusGPT had answered more than 50,000 questions over the past 12 months and had received the ‘Made with Patients Award’ by PFMD for Best Emerging Innovation. EasyLupus was also highlighted, including progress towards a voice-activated version currently in beta testing. Translators in attendance were warmly acknowledged and received Certificates of Appreciation for their valuable work.

Organisational achievements were also presented. These included the implementation of post-event interviews, a strong volunteer contribution amounting to 2,876 hours of work for the previous year, securing funding for the programme by April, having support from volunteers on web and IT matters, having an expanded Medical Advisory Board including both senior and younger lupologists, continuation of twice-yearly industry roundtables, and the appointment of Ricky Chotai as Special Advisor to the Board.

The session offered delegates a vivid sense of the scale, diversity, and energy of Lupus Europe’s work over the past year, while also reinforcing that these achievements are shared achievements made possible by the work of National Members and volunteers.

Top-Line Results from the Lupus Europe Member Survey

by Alain Cornet

Following the Celebration of Achievements, Alain Cornet, Lupus Europe Organisation Coach & Finance Lead, presented the top-line results of the Lupus Europe Member Survey, offering an initial overview of who national organisations are currently reaching through their membership and where important gaps or differences may exist. The survey gathered 1,665 responses from 24 member organisations and was presented not as a definitive picture of the entire lupus community, but as an important starting point to help further collective understanding of membership and as a way of identifying both strengths and possible blind spots.

The presentation explored a wide range of factors, including age, employment, socioeconomic status, culture, migration background, ethnicity, diagnosis profile, and member satisfaction. The results showed notable variation between countries in the age profile of members, the proportion of younger people involved, and the extent to which organisations appear to retain people over time. One important reflection from the survey was that while many members join relatively early after diagnosis, organisations seem to lose significant numbers of people over time, raising important questions about how groups can continue to remain relevant and supportive at different stages of peoples' lupus journeys.

The survey also highlighted inequalities and diversity-related considerations. Alain noted differences across countries in working status, financial difficulties, hospital access, cultural background, and migration status. While the majority of respondents belonged to the most prevalent cultural group in their country, there were also respondents from minority, migrant, or otherwise less represented backgrounds. This led to discussion not only about who national groups are currently reaching, but also about who may still be missing from their membership and what more might be needed to connect better with underrepresented groups.

Further questions explored practical issues affecting members' lives, such as understanding medical written materials, patient/doctor communication, transport to/from hospital, and opportunities to participate in clinical trials. Alain also highlighted that the survey can serve as a tool not only for Lupus Europe but for national groups themselves, and encouraged members to make use of the shared survey infrastructure if they wished to better understand their own membership or run additional surveys locally.

If you are interested in learning more about your country's results or the possibility of re-opening the member survey for your country, please get in touch with secretariat@lupus-europe.org

From Disadvantages to Solutions: Why Every Voice Does Not Matter…Yet

by Dr. Daniel Guimarães de Oliveira

Dr. Daniel Guimarães de Oliveira, internist and immunologist from Porto, Portugal, led a session focused on social determinants of health in lupus and on how these shape outcomes across the entire lupus patient pathway. The session was informative and interactive, with Dr. Oliveira encouraging delegates to reflect, respond, and bring their own experiences into the discussion. Framed around the wider Convention theme of “Every Voice Matters”, the presentation explored why, in practice, not every voice is yet equally heard or equally supported.

Dr. Oliveira began by introducing social determinants of health as the conditions in which people are born, grow, live, work, and age, and highlighted that these are non-medical factors which nevertheless have a major influence on health outcomes. He noted that while medical care is important, a substantial part of long-term outcomes is shaped by other factors, including wider social circumstances and behavioural patterns. He also emphasised that social determinants of health should not only be understood as barriers or risks but can also act as protective and health-promoting factors when the right support structures are in place.

A key part of the session focused on language and framing. Dr. Oliveira reflected on the differences between terms such as inequities, disparities, and vulnerabilities, and argued that “vulnerabilities” can sometimes offer a broader and more useful way of understanding where people may be at risk, especially when access to resources is limited or uneven. This led into a wider discussion on the global context: that social determinants of health can affect people before diagnosis, during the diagnostic journey, throughout treatment, and across the full lived experience of lupus.

Drawing on recently published research, Dr. Oliveira highlighted the measurable impact that factors such as poverty, education, income, a person’s living situation, or health literacy levels can have on damage accrual in lupus. He presented data showing that social circumstances can have a significant effect on hard outcomes, including mortality, and shared recent work from Sweden suggesting that factors including lower income, lower educational status, and social isolation are all associated with worse outcomes for lupus patients even in a healthcare system often perceived as strong or protective.

Another important theme was communication between doctors and patients. Dr. Oliveira highlighted that hurried consultations, inaccessible language, and low health literacy can all contribute to poorer understanding, lower treatment adherence, and worse outcomes. He reflected on the challenges clinicians face in adapting communication to very different people and circumstances, while also acknowledging that patients consistently need more time, clearer language, and better support to navigate lupus care effectively.

The session also explored how multiple disadvantages can accumulate and interact. Rather than acting in isolation, different vulnerabilities can compound one another and lead to a multiplying effect on risk. This helped frame lupus not simply as a medical condition, but as something experienced within a wider web of social, economic, and structural realities.

Importantly, the session did not stop at identifying problems. Dr. Oliveira was joined by Jeanette Andersen, Lupus Europe Chair, and they both moved the conversation towards practical solutions. They discussed the importance of increasing research in this field, integrating social determinants of health more meaningfully into lupus care and risk models, and building better systems for identifying and signposting support. Dr. Oliveira shared work from Portugal showing how local resources can be mapped and organised to help direct people towards practical support, whether for mental health, transport, financial hardship, or other needs.

Inspired by this work, delegates were invited to contribute to a practical exercise by identifying a small number of free or low-cost support resources in their own countries. National delegates volunteered to help gather information on support lines, mental health resources, transport help, and other forms of practical assistance in their countries. This action-oriented ending gave the session a strong collective dimension.

The session was a powerful reminder that improving lupus outcomes is not only about medicines or medical expertise, but also about recognising and addressing the wider conditions that shape peoples' lives.

Parallel Workshops A

Throughout the day, delegates took part in rounds of parallel workshops, bringing different aspects of the Convention theme, “Every Voice Matters”, to life through shared learning, discussion, and exchange. These workshops created space for delegates to reflect together on some of the practical and structural factors that can shape whether people living with lupus are heard, supported, and able to access the care and information they need. Aspects explored during the parallel workshops included digital illiteracy, economic factors, cultural factors, health literacy, and geographic aspects.

Following the first round of parallel workshops, delegates reconvened in plenary to share feedback, bringing together reflections from groups that had explored a range of barriers affecting lupus patients and lupus organisations. This reporting-back covered themes including diversity and ethnicity, health literacy, digital literacy, and geographic barriers to care, and highlighted both the differences across countries and the many areas where organisations can learn from one another.

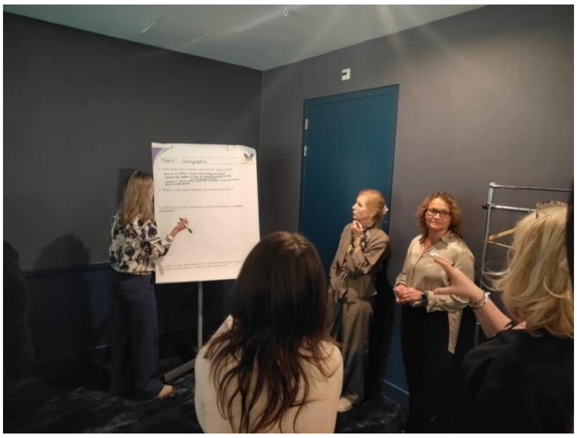
The discussions on diversity focused on the importance of reaching groups who may currently be underrepresented within patient organisations, including people from different ethnic and cultural backgrounds. Delegates shared examples of outreach in community settings, collaboration with doctors, more inclusive communication materials, and the value of making it visibly clear that organisations are open to everyone.

The health literacy group highlighted the importance of helping people understand information on lupus, communicate effectively with doctors, and access reliable information in ways that are meaningful and manageable for them. Delegates reflected on the role of peer support, patient workshops, simple educational materials, videos, and social media, as well as the need for healthcare professionals to be more aware of how to communicate with people who may have lower health literacy.

Digital literacy was explored from an organisational perspective, with delegates noting that many national groups increasingly rely on online meetings, emails, surveys, and digital tools, which can unintentionally exclude people who lack digital confidence, suitable devices, or internet access. Delegates shared examples of alternative approaches already in use, including phone support lines, handwritten letters, physical magazines, face-to-face events, and outreach in clinics.

The geographic access group focused on the impact of distance, rurality, transport, infrastructure, and the location of specialist services. Delegates reflected on how travel time, cost, energy, and uneven distribution of expertise can all delay diagnosis and treatment. Examples of possible solutions included travel reimbursement, telemedicine, mobile care, stronger referral pathways, and better awareness of existing support.

This workshop feedback session highlighted that while barriers differ from country to country, many National Member Organisations are already developing creative ways to address them, and there is considerable value in sharing these approaches across the European lupus community.



Introduction to Health Technology Assessment

by Jeanette Andersen

Jeanette Andersen, Lupus Europe Chair, then gave a brief introduction on Health Technology Assessment (HTA), explaining why this is becoming increasingly important for lupus patient organisations at a time when more new treatments are emerging. She outlined the basics of HTA as a process used to assess the value of health technologies, including medicines and other treatments, and explained that this involves not only clinical effectiveness and safety, but also economic, social, ethical, legal, and organisational considerations.

Jeanette also introduced the new EU HTA regulation, which came into application in 2025 and aims to strengthen cooperation across Europe and improve the efficiency and consistency of assessment processes. While final reimbursement decisions still remain at national level, the new framework is intended to support a more coordinated European approach and, hopefully, faster and fairer access to new treatments. Jeanette emphasised that patient representatives have an important role to play in these processes, particularly in providing stakeholder input on what treatments mean in real life for patients and their families.

The session concluded with an invitation for interested delegates and national organisations to take part in a future online HTA Summit organised by Lupus Europe. This HTA Summit would help strengthen understanding of the process and support patient representatives in becoming more active and informed participants when new lupus treatments are assessed and discussed at national level.

What is Health Technology Assessment (HTA)?

HTA is defined as a multidisciplinary process that uses explicit methods to determine the value of a health technology at different points in its lifecycle. The purpose of HTA is to inform **decision-making** to promote an equitable, efficient, and high-quality health system (O'Rourke 2020)

A Few Tangible Actions

by Andreas Panteli

Andreas Panteli from Lupus Suisse then led a short but powerful, interactive session centred on bias, invisibility, and the different ways in which voices can go unheard. Rather than beginning with practical recommendations, Andreas invited delegates into a reflective exercise. With their eyes closed, participants were asked to imagine three different lupus patient scenarios: a patient whose symptoms are repeatedly minimised before diagnosis, a patient facing language and cultural barriers after moving to a new country, and a patient living with the burden of an illness that may not be visible to others.

After the exercise, Andreas asked delegates to reflect on how they had imagined each of the patients. The discussion revealed how easily assumptions can arise around gender, ethnicity, age, visibility, and experience, and opened a wider conversation about the need to recognise personal and collective bias when thinking about support, access, and representation. Delegates also connected the imagined stories to their own lives, with several sharing that they could strongly recognise themselves in one or more of the scenarios.

The discussion that followed highlighted important dimensions of living with lupus, including the experience of not being believed, the challenge of being misunderstood even when speaking one's own language, the burden of hiding symptoms from family or colleagues, and the emotional complexity of wanting to live fully while also managing limitations and guilt. Andreas' session offered a thoughtful and unique way to bring the Convention theme of “Every Voice Matters” into personal focus, reminding delegates that visibility, understanding, and inclusion also require each of us to reflect on the assumptions we carry.

Parallel Workshops B

The afternoon saw the second round of parallel workshops, continuing the collective exploration of different aspects of “Every Voice Matters”. This round of workshops focused on isolation, men, economic factors, and digital literacy, with delegates reflecting on how these different aspects can affect both access to lupus care and the ability of patient organisations to reach and support people effectively.

The group discussing isolation reflected on how difficult it can be for organisations to support people who are disconnected, hard to reach, or not visibly engaged with healthcare systems or patient groups. Delegates noted that the meaning of isolation may vary from country to country and that understanding local context is therefore essential before solutions can be developed. Examples of existing good practice included free helplines, self-management support, one-to-one contact with new members, and involving professionals such as social workers, psychologists, and general practitioners who may be better placed to identify those most at risk of isolation.

The workshop on men highlighted the continuing need for more visibility, more research, and more understanding around lupus in men. Delegates reflected that men may sometimes access care later, often only once symptoms are more severe, and that this may influence how they are perceived by healthcare professionals and how quickly they are taken seriously. The group discussed the importance of involving more men in patient organisations, sharing male patient stories, carrying out needs assessments, and ensuring communication materials visibly represent men as part of the lupus community. The upcoming Lupus Europe Men’s Panel was also noted as an important and timely initiative.

The economic workshop focused on the impact of financial limitations both on people living with lupus and on the organisations trying to support them. Delegates discussed how limited funding can restrict access to education, events, printed materials, administration, and face-to-face support. Existing responses included collaboration with pharmaceutical companies, government or national funding where available, support from larger rheumatology organisations, crowdfunding, and tax-funded programmes.

The digital literacy group reflected specifically on how low digital literacy can affect access to lupus care itself. Delegates noted that in some countries, healthcare systems are now so digital that people who lack confidence with technology or access to suitable devices can struggle even to navigate appointments, receive information, or use patient-facing systems. The group also highlighted the need to reduce stigma and shame around digital illiteracy, since many people may be reluctant to admit they are struggling.

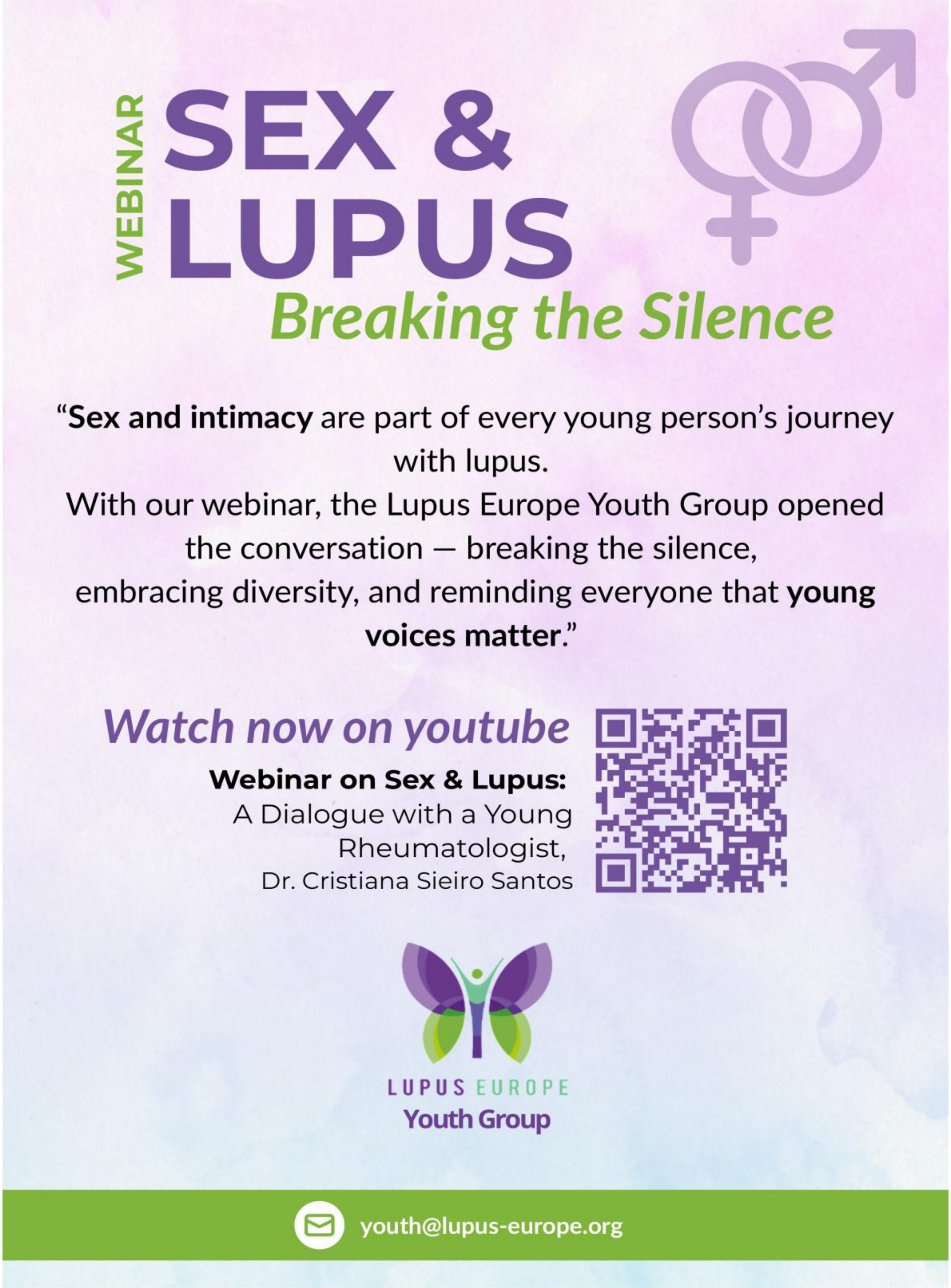
This second parallel workshop session reinforced the central message that making every voice matter requires more than intention alone. It demands attention to the structural, social, financial, and practical barriers that shape whether people are able to be seen, heard, informed, and supported.

Poster Tour

The afternoon concluded with the Poster Tour, where delegates had the opportunity to hear short presentations on projects, initiatives, and tools developed by different National Member Organisations as well as by the Lupus Europe Youth Group. This created a lively and practical exchange of ideas, allowing delegates not only to celebrate one another’s work but also to gather inspiration, share good practice, and identify approaches that might be adapted in their own countries.

Lupus Europe Youth Group

The Lupus Europe Youth Group presented their poster on “Sex and Lupus: Breaking the Silence”, explaining that they had chosen the topic because it is both important and often difficult to address in clinical settings. They reflected on how questions around sex and intimacy are not always easy for young people to raise with doctors, and how doctors do not always raise the topic either. This webinar was presented as one example of the Lupus Europe Youth Group’s wider effort to create accessible and relevant educational content for young people (18–35) living with lupus in Europe.



WEBINAR

SEX & LUPUS

Breaking the Silence

“**Sex and intimacy** are part of every young person’s journey with lupus.
With our webinar, the Lupus Europe Youth Group opened the conversation — breaking the silence,
embracing diversity, and reminding everyone that **young voices matter**.”

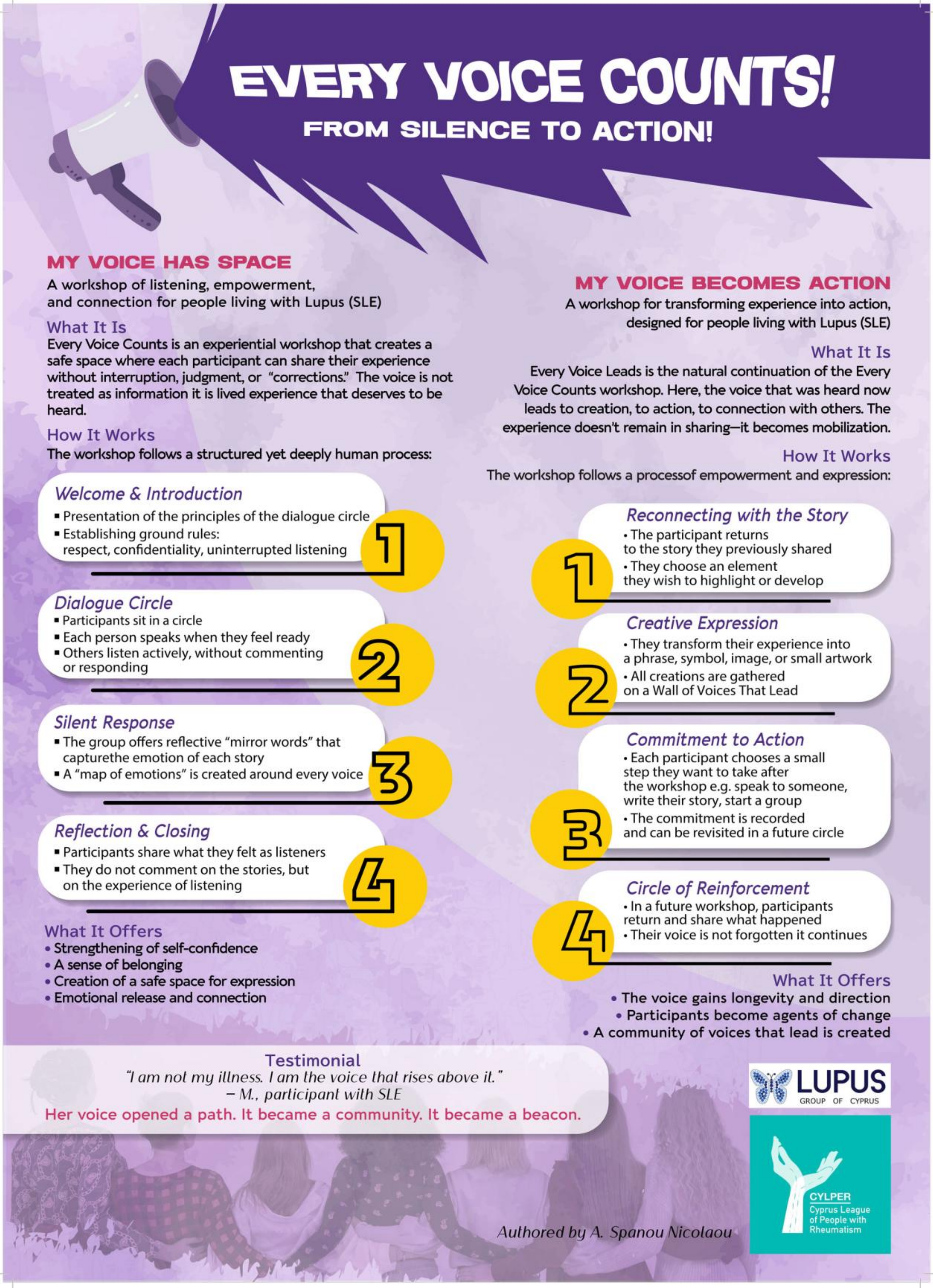
Watch now on youtube

Webinar on Sex & Lupus:
A Dialogue with a Young
Rheumatologist,
Dr. Cristiana Sieiro Santos

LUPUS EUROPE
Youth Group

youth@lupus-europe.org

CYPLER shared a poster on a series of workshops focused on voice, expression, and empowerment. These workshops were designed to create safe spaces in which participants could share experiences, feel heard without judgement, and gradually move from reflection towards action. Through listening, expression, and creative engagement, the workshops aimed to support confidence, belonging, emotional release, and small but meaningful steps forward.



EVERY VOICE COUNTS!

FROM SILENCE TO ACTION!

MY VOICE HAS SPACE

A workshop of listening, empowerment, and connection for people living with Lupus (SLE)

What It Is

Every Voice Counts is an experiential workshop that creates a safe space where each participant can share their experience without interruption, judgment, or "corrections." The voice is not treated as information it is lived experience that deserves to be heard.

How It Works

The workshop follows a structured yet deeply human process:

1 *Welcome & Introduction*

- Presentation of the principles of the dialogue circle
- Establishing ground rules: respect, confidentiality, uninterrupted listening

2 *Dialogue Circle*

- Participants sit in a circle
- Each person speaks when they feel ready
- Others listen actively, without commenting or responding

3 *Silent Response*

- The group offers reflective "mirror words" that capturethe emotion of each story
- A "map of emotions" is created around every voice

4 *Reflection & Closing*

- Participants share what they felt as listeners
- They do not comment on the stories, but on the experience of listening

What It Offers

- Strengthening of self-confidence
- A sense of belonging
- Creation of a safe space for expression
- Emotional release and connection

MY VOICE BECOMES ACTION

A workshop for transforming experience into action, designed for people living with Lupus (SLE)

What It Is

Every Voice Leads is the natural continuation of the Every Voice Counts workshop. Here, the voice that was heard now leads to creation, to action, to connection with others. The experience doesn't remain in sharing—it becomes mobilization.

How It Works

The workshop follows a processof empowerment and expression:

1 *Reconnecting with the Story*

- The participant returns to the story they previously shared
- They choose an element they wish to highlight or develop

2 *Creative Expression*

- They transform their experience into a phrase, symbol, image, or small artwork
- All creations are gathered on a Wall of Voices That Lead

3 *Commitment to Action*

- Each participant chooses a small step they want to take after the workshop e.g. speak to someone, write their story, start a group
- The commitment is recorded and can be revisited in a future circle

4 *Circle of Reinforcement*

- In a future workshop, participants return and share what happened
- Their voice is not forgotten it continues

What It Offers

- The voice gains longevity and direction
- Participants become agents of change
- A community of voices that lead is created

Testimonial

"I am not my illness. I am the voice that rises above it."
– M., participant with SLE

Her voice opened a path. It became a community. It became a beacon.

LUPUS GROUP OF CYPRUS

CYLPER
Cyprus League of People with Rheumatism

Authored by A. Spanou Nicolaou

Lupus Iceland

Lupus Iceland presented work on translation and access to information. Following one member’s diagnosis and difficulty finding accessible information in Icelandic, the organisation began translating Lupus Europe’s “Lupus 100” resource into Icelandic. The group also highlighted a practical sun-awareness initiative linked to an unusually sunny Icelandic summer, helping people gain access to sunscreen and sun-protective items.

LUPUS ICELAND

Welcome
Lupus Warriors

ARTICLES IN NEWSPAPERS

RADIO INTERVIEWS

Hats with UPF50

Monthly meetings

Answer questions and concerns

Give new information about Lupus

Import sun protection products like hats and sunscreen that otherwise is not sold in Iceland

Translate The 100 Questions

FUN FACTS

I LIKE TO SPEND TIME
WITH MY FAMILY

Lupus Sweden

Lupus Sweden presented several initiatives, including the annual Lupus Day held in different cities across the country with the aim of making the day more accessible, as well as a children's book developed to help explain lupus to younger children living with an affected parent. The book, together with the group's newer lupus awareness pin, reflects the organisation's aim of raising visibility, spreading knowledge, and reducing loneliness among people living with lupus and their families.

Lupus Sweden 2025 – fighting to make every voice heard

In Sweden we have the Swedish Rheumatism Organization that has more than 38000 members. As a part of it, we formed a lupus association in 2017; Riksföreningen för SLE. Our association has almost 160 members and aims to spread knowledge about lupus and counteract loneliness. We have a Facebook group where members can discuss freely. We try to post a lot about research in the group so the members are up to date with the latest news.

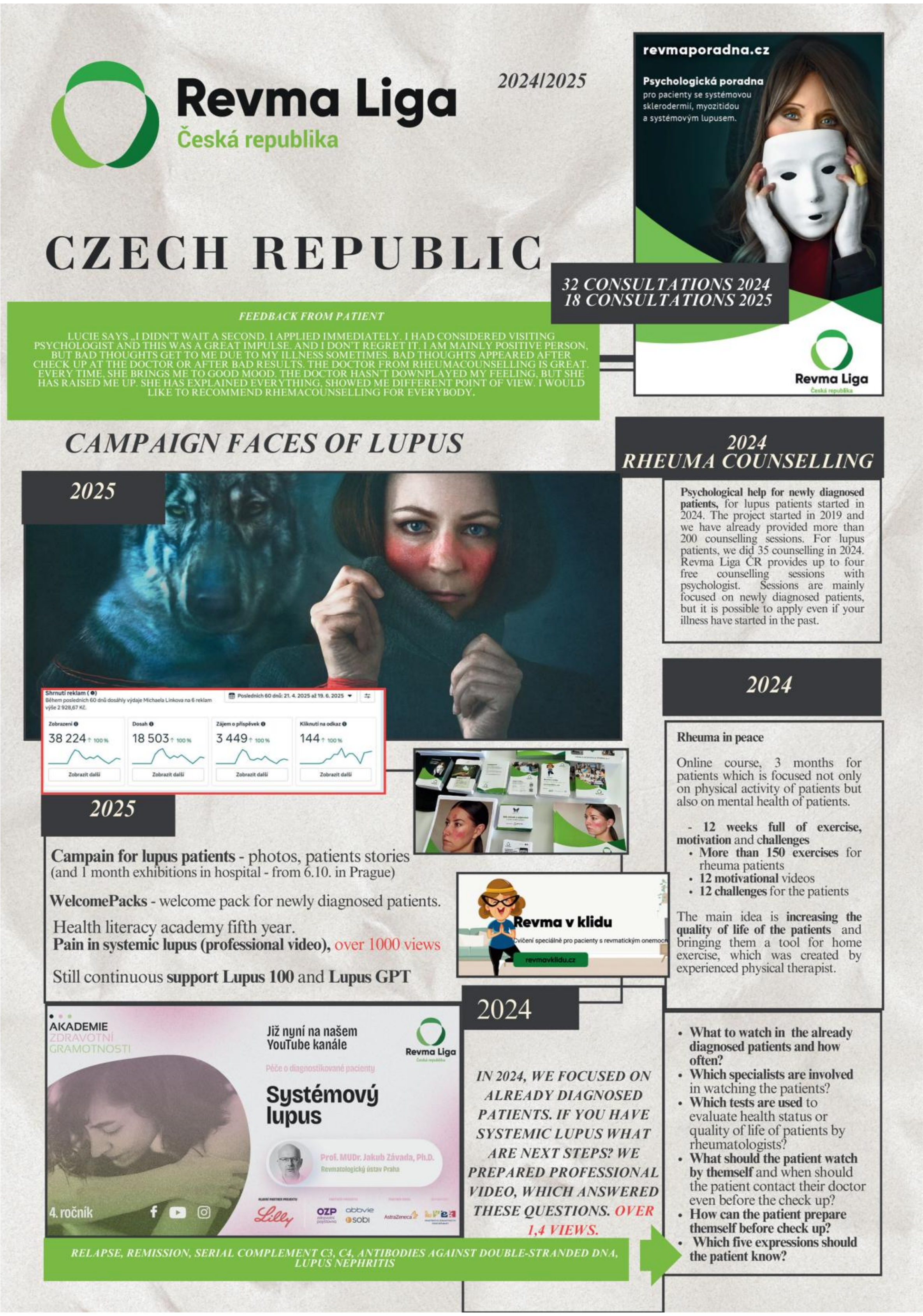
The World Lupus Day takes place every year on the 10th of May and we try to arrange a Swedish theme day around this date. We started this tradition in 2013 and it was a success! Arranging this day was the main reason for us to start the association. We try to have the lupus day in different cities in Sweden, because we want all members across our country to feel important and included.

In 2024 we released a book about lupus that was developed for younger children. The book aims to explain what it is like to live with a parent that has lupus. It is called: "My mother can have a butterfly on the nose" and has beautiful drawings. It is so far only available in Swedish.

We have also recently developed a new lupus/SLE pin. Our aim with selling it is to raise money for research about lupus and making lupus more visible.

The Lupus Czech Group

The Lupus Czech Group highlighted two projects: psychological support through counselling, and health literacy videos designed to help people after diagnosis understand what comes next, what they can expect, and how to navigate the early period following diagnosis.



Revma Liga
Česká republika

2024/2025

CZECH REPUBLIC

revmaporadna.cz

Psychologická poradna
pro pacienty se systémovou sklerodermií, myozitidou a systémovým lupusem.

32 CONSULTATIONS 2024
18 CONSULTATIONS 2025

FEEDBACK FROM PATIENT

LUCIE SAYS „I DIDN'T WAIT A SECOND. I APPLIED IMMEDIATELY. I HAD CONSIDERED VISITING PSYCHOLOGIST AND THIS WAS A GREAT IMPULSE. AND I DON'T REGRET IT. I AM MAINLY POSITIVE PERSON, BUT BAD THOUGHTS GET TO ME DUE TO MY ILLNESS SOMETIMES. BAD THOUGHTS APPEARED AFTER CHECK UP AT THE DOCTOR OR AFTER BAD RESULTS. THE DOCTOR FROM RHEUMACOUNSELLING IS GREAT. EVERY TIME, SHE BRINGS ME TO GOOD MOOD. THE DOCTOR HASN'T DOWNPLAYED MY FEELING, BUT SHE HAS RAISED ME UP. SHE HAS EXPLAINED EVERYTHING, SHOWED ME DIFFERENT POINT OF VIEW. I WOULD LIKE TO RECOMMEND RHEMACOUNSELLING FOR EVERYBODY.

CAMPAIGN FACES OF LUPUS

2025

Shrnutí reklam
Během posledních 60 dnů dosáhly výdaje Michaela Linkova na 6 reklam výše 2 928,67 Kč.
Posledních 60 dnů: 21. 4. 2025 až 19. 6. 2025

Zobrazení	Dosah	Zájem o příspěvek	Kliknutí na odkaz
38 224 ↑ 100 %	18 503 ↑ 100 %	3 449 ↑ 100 %	144 ↑ 100 %
Zobrazit další	Zobrazit další	Zobrazit další	Zobrazit další

2025

Campain for lupus patients - photos, patients stories (and 1 month exhibitions in hospital - from 6.10. in Prague)

WelcomePacks - welcome pack for newly diagnosed patients.

Health literacy academy fifth year.
Pain in systemic lupus (professional video), over 1000 views

Still continuous **support Lupus 100** and **Lupus GPT**

2024
RHEUMA COUNSELLING

Psychological help for newly diagnosed patients, for lupus patients started in 2024. The project started in 2019 and we have already provided more than 200 counselling sessions. For lupus patients, we did 35 counselling in 2024. Revma Liga ČR provides up to four free counselling sessions with psychologist. Sessions are mainly focused on newly diagnosed patients, but it is possible to apply even if your illness have started in the past.

2024

Rheuma in peace

Online course, 3 months for patients which is focused not only on physical activity of patients but also on mental health of patients.

- **12 weeks full of exercise, motivation** and **challenges**
  - **More than 150 exercises** for rheuma patients
  - **12 motivational** videos
  - **12 challenges** for the patients

The main idea is **increasing the quality of life of the patients** and bringing them a tool for home exercise, which was created by experienced physical therapist.

Revma v klidu
Cvičení speciálně pro pacienty s revmatickým onemoc
revmavklidu.cz

AKADEMIE
ZDRAVOTNÍ
GRAMOTNOSTI

Již nyní na našem YouTube kanále

Péče o diagnostikované pacienty

Systémový lupus

Prof. MUDr. Jakub Závada, Ph.D.
Revmatologický ústav Praha

4. ročník

2024

IN 2024, WE FOCUSED ON ALREADY DIAGNOSED PATIENTS. IF YOU HAVE SYSTEMIC LUPUS WHAT ARE NEXT STEPS? WE PREPARED PROFESSIONAL VIDEO, WHICH ANSWERED THESE QUESTIONS. OVER 1,4 VIEWS.

RELAPSE, REMISSION, SERIAL COMPLEMENT C3, C4, ANTIBODIES AGAINST DOUBLE-STRANDED DNA, LUPUS NEPHRITIS

- **What to watch in the already diagnosed patients and how often?**
- **Which specialists are involved** in watching the patients?
- **Which tests are used** to evaluate health status or quality of life of patients by rheumatologists?
- **What should the patient watch by themself** and when should the patient contact their doctor even before the check up?
- **How can the patient prepare themself before check up?**
- **Which five expressions should the patient know?**

Lupus Norway

Lupus Norway shared examples of collaboration with a university hospital, new brochures developed with clinical support, and a regular newsletter used to keep members informed about research, events, and practical topics.

NORSK REVMATIKERFORBUND

The University hospital in Oslo has a yearly arrangement for patients with connective tissue diseases, including Lupus.

We have a stand where we inform patients/others that are interested in SLE.

We have published two new brochures in collaboration with Astra Zecena and MD PhD Sigrid Reppe Moe.

"Practical tips for improving your daily life" and ***"Find out more about SLE"***

We also publish a newsletter for our members twice a year, where we focus on lupus related topics which are interesting to know, such as research projects and sun protection. We also share patients' stories and inform them about our participation in different conferences, EULAR etc.

Sammen for et friskere liv

NHN Intern - kan deles

Lupus Belgium

Lupus Belgium presented their new website, magazines, yoga work, and therapeutic workshops developed with clinicians, while also highlighting their annual Lupus Day.

Lupus Erythémateux

BELGIUM

NEW WEBSITE LAUNCH

On May 10th, we launched the redesigned www.lupus.be created with the support of Lupus Europe.

LE LIEN

We proudly published two editions of Le Lien, our magazine sharing the latest advances and perspectives on lupus. And we're continuing in the coming year!

YOGA WORKSHOP

a space for balance, relief, and connection during Clair's ASBL Special Day. And we're continuing in the coming year!

THERAPEUTIC WORKSHOP

We support therapeutic workshops with UCLouvain, empowering patients and caregivers through training around lupus.

GROWING COMMUNITY

Follow us on Facebook, where our community of 3,000+ followers stays connected, informed, and supported.

OUR ASSOCIATION'S DAY : OCTOBER 18TH

Join us for our annual day, focused on :

- Troublesome Symptoms
- New Treatments

Lupus Italy

Lupus Italy presented a wide range of awareness and support activities, including continued support to lupus clinics, public awareness stands and campaigns, illumination of landmarks in purple for World Lupus Day, participation in surveys and projects, and their “Less is More” initiative focused on identifying excellence in lupus care from the patient perspective.

Gruppo LES Italiano ODV

LIVE BROADCASTS

We continue our live broadcast service, launched in April 2020, where Lupus specialists discuss different topics and answer patients’ questions, aiming to clear up all their doubts. We host these live events once a month.

At the same time, we regularly post video interviews with Italian Lupus specialists on our social networks, covering a variety.

LUPUS CLINICS

We continue to support and provide financial assistance to Lupus Clinics throughout Italy.

WORLD LUPUS DAY

Every year we celebrate ‘World Lupus Day - May 10th’
We take part in press conferences, air commercials on regional television, organize regional doctor–patient meetings and press events, and distribute Sunflowers for fundraising.
In addition, on May 10th, in honour of World Lupus Day, 17 buildings in various Italian cities were illuminated in purple

OCTOBER - LUPUS AWARENESS MONTH

October is “Lupus Awareness Month”, dedicated to spreading information about Lupus and, above all, to raising funds.
This year we have planned many activities, including the distribution of Saintpaulia violets at stalls set up in several Italian cities.

Main Projects:

La tua esperienza può cambiare le cose.
Partecipa al questionario

YOUR VOICE MATTERS!!!!

Do you have lupus? Share your experience with the centres where you receive care. Our new survey has one clear goal: to listen to you—so we can truly improve the care and support offered to people living with Lupus.

- It only takes 5 minutes
- It’s completely anonymous
- Your input can make a real difference for many others

Participate now and help us improve lupus care. Fill out the questionnaire today!

SLE is more - Il Lupus al Centro
The first campaign to certify ‘Italian Centers of Excellence’ for the treatment of Systemic Lupus Erithematosus
https://www.lupus-italy.org/cose-il-lupus/centri-certificati/

LES is more
Il Lupus al Centro
Il primo riconoscimento di qualità dei centri di cura del LES in Italia

Se sei un **medico** e lavori in una struttura specializzata nella cura del Lupus **compila il form: riceverai il questionario per partecipare l’indagine!**

Lupus suisse

Lupus suisse shared their work on a magazine issue focused on men and lupus, a collaborative cross-border Lupus Run organised together with patients in Germany and Austria, and the translation of Lupus Europe's "Lupus100" resource into French. This was a particularly strong example of how connections made within the Lupus Europe community can lead directly to new joint initiatives between countries.

Magazin für Lupus
Erythematodes Betroffene
Magazine pour les personnes
concernées par
le lupus érythémateux
www.lupus-suisse.ch

2025

lupus

Mann und Lupus
Homme et lupus
8

Neuartiger Behandlungsansatz mit Interleukin-2
Nouvelle approche thérapeutique avec l'interleukine-2
7

Plötzlich war alles anders
Soudain, tout a changé
22

Lupus-Gespräche in den sozialen Medien
Discussions dans les réseaux sociaux
26

In an effort to support the theme of diversity and inclusivity, we decided to dedicate our latest magazine issue to discuss Men living with Lupus.
We then initiated it starting with concept development, content creation design & layout, to printing & distribution to our members and supporters. More than 600 magazines have been printed.
We have 9% male members and never had an issue on the topic in over ten years and 22 issues.

lupus suisse

Who Resolution on Skin Diseases as a Global Public Health Priority

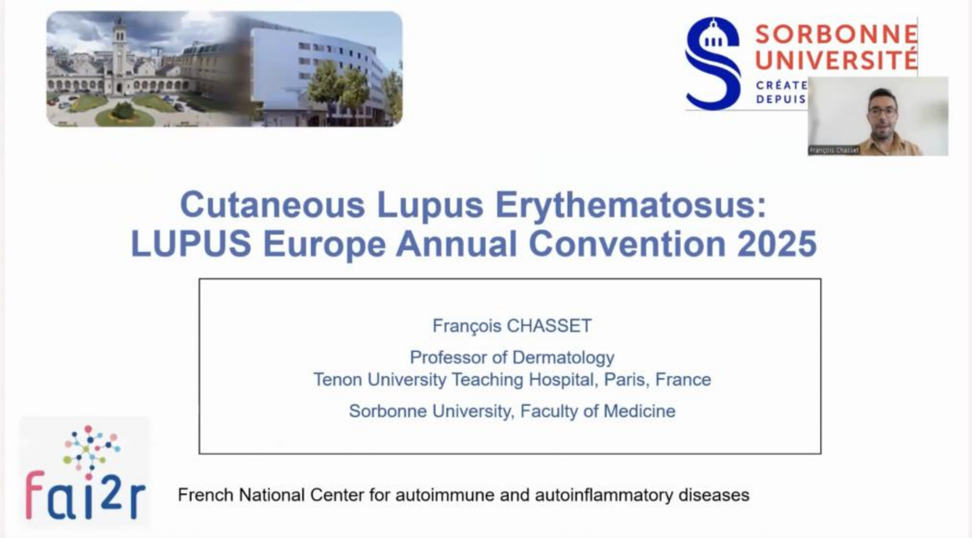
by Annemarie Sluijmers

Before the session on skin lupus, Annemarie Sluijmers, Lupus Europe Vice Chair and ePAG in ERNSkin, gave a short presentation on the World Health Assembly Resolution on "Skin diseases as a global public health priority", adopted in May 2025. She highlighted why this matters for the lupus community, noting that skin involvement affects 75–80% of people with SLE over time and is the first manifestation in around 20% of cases.

Annemarie outlined the key elements of the Resolution, including support for a global action plan, greater health investment, stronger research and data collection, more equitable access to care, and better integrated services. She emphasised that this represents not only an important policy development, but also a wider global commitment to improving the lives of people affected by skin disease. This provided very relevant context for the clinical presentation that followed on cutaneous lupus erythematosus.

Advances in the Treatment of Skin Lupus

by Prof. François Chasset



Cutaneous Lupus Erythematosus:
LUPUS Europe Annual Convention 2025

François CHASSET
Professor of Dermatology
Tenon University Teaching Hospital, Paris, France
Sorbonne University, Faculty of Medicine

French National Center for autoimmune and autoinflammatory diseases

Prof. François Chasset, dermatologist at Tenon University Teaching Hospital in Paris, delivered a video presentation on cutaneous lupus erythematosus (CLE), focusing on how skin lupus presents, why recognising its different subtypes matters, and where treatment is beginning to move. His session offered delegates a clear overview of an area of lupus that can have major physical and psychological consequences, but which still has relatively limited treatment options, especially for people with isolated skin disease.

Prof. Chasset began by explaining that there is a continuous spectrum between isolated cutaneous lupus and skin involvement that occurs as part of systemic lupus erythematosus (SLE). He highlighted that skin involvement is often one of the first manifestations of lupus and that most people with SLE will experience some form of cutaneous involvement over time. He also stressed an important diagnostic point: there are currently no formal diagnostic criteria for CLE, and classification criteria should not be confused with diagnosis criteria.

A central focus of the session was the different CLE subtypes. Prof. Chasset explained that cutaneous lupus is classically divided into acute, subacute, and chronic forms, with chronic CLE including discoid lupus, chilblain lupus, lupus panniculitis, and lupus tumidus. He emphasised that identifying the correct subtype is very important, because these forms differ not only in appearance and location, but also in their association with systemic disease and in their potential to cause permanent damage. In particular, chronic forms such as discoid lupus and lupus panniculitis can lead to irreversible scarring and permanent hair loss.

He also highlighted that some subtypes are more closely associated with systemic lupus than others. Acute cutaneous lupus is almost always linked to SLE, while subacute CLE is associated with systemic disease in a substantial proportion of cases. Prof. Chasset also pointed out that subacute CLE can sometimes be drug-induced, meaning that a review of recently introduced medications is an important part of assessment.

The session then moved to treatment. Prof. Chasset explained that current guidance for isolated CLE still places strong emphasis on topical treatment and antimalarials, particularly hydroxychloroquine, which remains the cornerstone of treatment. Methotrexate is often considered a preferred second-line option, with other drugs such as retinoids, dapsone, mycophenolate mofetil, thalidomide, and lenalidomide used in selected cases. Where CLE occurs in the setting of systemic lupus, treatment options can also include biologic therapies such as anifrolumab.

Alongside medication, Prof. Chasset stressed the importance of prevention and supportive management, including photoprotection, smoking cessation, and review of drugs that may trigger or worsen cutaneous lupus. He also highlighted the major impact CLE can have on quality of life. The session concluded on a hopeful note, with Prof. Chasset highlighting several emerging therapies currently being studied in clinical trials.

Parallel Workshops C

After Prof. Chasset’s session, delegates went into a further round of interactive workshops, this time focusing on aspects such as lupus-like symptoms, geographic barriers, economic factors, and cultural factors. The discussion highlighted both the diversity of experiences across different European countries, and the common challenges organisations face when trying to support people living with lupus more effectively and inclusively.

The discussion around lupus-like symptoms focused on the difficult position of people who present with symptoms suggestive of lupus but who do not yet have a formal diagnosis. Delegates reflected on the need for clearer next steps, better guidance for organisations, training in active listening, buddy systems, and better information materials both for patients and for doctors. Skin manifestations were discussed as an especially important area, since they are often among the first visible signs of lupus.

The geographic workshop reflected on both physical distance and linguistic or regional variation as barriers to care and to organisational participation. Delegates discussed examples such as large countries, rural areas, islands, and multilingual contexts, and shared practical ideas including decentralised events, live or online access, travel reimbursement, and stronger links between organisations and local care settings.

The economic group again highlighted how strongly financial realities can shape what is possible for both patients and organisations. Among the more concrete ideas raised was the importance of recognising sunscreen as a medical necessity for people with lupus, and the possibility of working towards stronger formal recognition of this need.

The culture-related workshop reflected on how cultural background can shape whether people feel welcomed, represented, and understood within organisations. The group discussed ideas such as identifying champions from different communities, preparing organisations through training and awareness, developing more personalised ways of welcoming people, and improving understanding of intersectionality.

This workshop session continued to bring the Convention theme of “Every Voice Matters” into practical focus, showing how barriers to access, belonging, and visibility may arise in different ways, but also how National Member Groups can share solutions and learn from one another.

Great Resources for You

By the Lupus Europe Board

The day proceeded with a session titled “Great Resources for You”, designed to highlight a range of practical tools, projects, and opportunities that National Member organisations could immediately use, adapt, or bring back to their own countries. The session brought together tools, patient information resources, AI-driven support, organisational development opportunities, and ready-to-use communication materials, making it one of the most practically focused sessions of the Convention.

Elfriede Wijsma, Lupus Europe Vice Chair and Treasurer, presented the European version of the Consultation Cards. The Consultation Cards were originally developed by the Dutch lupus patient organisation NVLE in collaboration with doctors and later adapted for a wider European context together with ERN ReCONNET and Lupus Europe. The cards are simple but highly practical tools intended to support the consultation itself. They invite patients to reflect in advance on which symptoms are bothering them most, score the burden of these symptoms, and identify their top three questions for the doctor. The cards are available in three languages (English, German, Portuguese) with many more to come.

Francesca Marchiori, Lupus Europe Board Member, presented Lupus100, one of Lupus Europe’s most ambitious projects. The aim of Lupus100 is to give people with lupus access to medically valid, reliable information in clear, patient-friendly language, while also addressing the widespread misinformation about lupus online. At present, 19 languages are already live, with further expansion planned for 2026, making Lupus100 an important shared resource for National Members seeking to improve access to trustworthy lupus information in their own countries.

Jeanette Andersen, Lupus Europe Chair, then presented LupusGPT, Lupus Europe’s multilingual artificial intelligence (AI) tool designed to give people with lupus medically reliable answers to their general lupus questions, in dialogue format. LupusGPT has already answered more than 50,000 questions since its launch. Jeanette also highlighted EasyLupus, a simpler-language feature of LupusGPT, designed for people who may struggle with lower health literacy or severe brain fog. Current work is focused on expanding its accessibility further, including through voice activation.

Annemarie Sluijmers, Lupus Europe Vice Chair and Secretary, presented Lupus Europe’s Capacity Building Programme. The programme, launched in 2020, is a way in which Lupus Europe can help National Members grow through small financial support, advice, expertise, or connections. National Members can apply for support for new projects of benefit to lupus patients, including projects aimed at better communication with members, information and resource provision, website or social media improvement, and events specifically targeted at harder-to-reach groups.

The session also introduced a new National Member leaflet concept, developed so National Members could receive printed and electronic leaflet templates in their own languages and easily adapt them for their own organisation. Lupus Europe also committed to supporting interested groups with printing and sending the final leaflets.

If your National Member organisation is interested in learning more about any of these resources, please get in touch with mailto:secretariat@lupus-europe.orgs

Youth in Focus – Every Voice Matters

with Marina Pietri and Rita Vieira from the Lupus Europe Youth Group

Marina and Rita introduced the work of the Lupus Europe Youth Group, offering delegates a clear and thoughtful reflection on why young people living with lupus may need distinct forms of support, different spaces for discussion, and targeted opportunities to connect. Drawing on both personal experience and broader Youth Group discussions, they highlighted that being diagnosed with lupus at a younger age often intersects with a particularly unstable and demanding period of life, when many people are still studying, beginning their careers, building relationships, and trying to imagine their future.

The presentation explored why young people's experiences may differ to those of older adults in important ways. Delegates heard about the added pressures of navigating education, early employment, financial strain, mental health challenges, uncertainty, and social expectations while also trying to understand and manage a chronic disease. Marina and Rita reflected on how difficult it can be to balance the desire to live fully and freely with the realities of lupus, and why young people may often feel unseen or insufficiently heard in lupus spaces not specifically designed for young people.

They argued that a separate or youth-focused space can be valuable not because young people's problems are "more important", but because they are specific and deserve to be understood in their own context. The discussion also touched on denial, the difficulty some young people may have in accepting a diagnosis, and the challenge of reaching those who are not yet ready to engage.

The Youth Group also shared examples of Lupus Europe projects they have already been involved in, including work linked to the Lupus Brain Fog Severity Scale, LUPUS ALERT, SLAKE, and the webinar on sex and lupus. Looking ahead, they invited delegates to engage with future youth-focused activities, including upcoming webinars on lupus and drugs and alcohol and on fertility and family planning.

The session was an important reminder that if every voice matters, then younger voices also need spaces where they can be heard clearly, safely, and on their own terms.

Celebration of Achievements: National Members

National Member delegates then took the floor in an inspiring continuation of the Celebration of Achievements session, adding their own milestones to Lupus Europe's collective tree. While the green leaves represented Lupus Europe's own achievements, the yellow leaves were used to capture the work, progress, and successes of the National Member organisations themselves. Together, these leaves transformed the tree into a vivid visual representation of unity, growth, and shared progress across the European lupus community.

The yellow leaves reflected the remarkable breadth of work National Members have carried out over the past year, from information and awareness activities, to events, patient support, and very practical support for members. Visible examples pointed to initiatives such as newspaper articles, proposals submitted to state authorities on issues affecting lupus patients, World Lupus Day celebrations, the Rheuma in Peace course, national conventions, video-based awareness work reaching more than 100,000 views, and wider national projects such as Your Voice Matters in Italy.

The session reinforced that Lupus Europe is not "only" an organisation, but also a collective effort built through the work of its members. It also highlighted the interdependence between European-level action and national-level activity. The result was both symbolic and practical: a collective picture of a European lupus community that is growing stronger through shared effort, shared learning, and shared commitment.

Thieves' Market

The Convention also included a Thieves’ Market, where National Members briefly presented aspects of their organisations, projects, and current activities to the wider Convention. This created a highly practical space for exchange, allowing delegates to discover ideas, approaches, and initiatives from across the European lupus community and to take inspiration back to their own National Member groups.

Among the presentations, Wendy Zacouris, Chair of NVLE, shared an overview of its structure and work. Founded in 1980 and run entirely by volunteers, NVLE supports people living not only with lupus, but also APS, scleroderma, and MCTD. The presentation highlighted NVLE’s broad range of activities, including information provision, research involvement, guideline development, and advocacy, as well as practical tools such as the Consultation Cards developed together with clinicians.

Marina and Rita from the Lupus Europe Youth Group also took the floor to speak directly to delegates about the Youth Group, its purpose, and the importance of involving more young people living with lupus in national groups. They encouraged National Members to get in touch with the Youth Group, to share ideas, and to think more actively about how to create space for younger voices within their own organisations.

Andri Spanou-Nicolaou from CYPLER presented “Artfully Design Your Life”, a creative and reflective workshop approach designed especially for people living with chronic illness who may feel unseen, unheard, or unable to express themselves easily. The presentation highlighted expression through colour, mindfulness, and non-verbal forms of participation.

Marko Mladenovic from Lupus Serbia introduced the Serbian organisation to delegates. As the newest Associate Member of Lupus Europe, his contribution marked an important moment of welcome and visibility for the Serbian lupus group. Marko spoke about the organisation’s development, its cooperation with lupus physicians in Serbia, and recent awareness efforts.

Jeanette Andersen spoke about Lupus Denmark’s “Know Your Lupus” course for newly diagnosed patients, a structured programme that has been running since 2013. Originally developed as a face-to-face programme and later adapted into an online format, the course offered a strong example of how national groups can provide practical, staged support for people at the beginning of their lupus journey.

The Thieves’ Market added a dynamic and community-focused dimension to the Convention. It highlighted the diversity, creativity, and commitment of national member groups across Europe, and the value of creating space for practical exchange between organisations working in different contexts but towards shared goals.

From Ideas to Action: Unlocking Potential and Taking Next Steps Together

In the next round of sessions, delegates moved from discussion into prioritisation and action planning. Building on the themes explored throughout the Convention, ideas turned into tangible, realistic actions that Lupus Europe and its National Members could potentially take forward together. These proposed actions were then displayed visually, and delegates were invited to vote for the topics they felt should be prioritised. This created a very practical and collective exercise, helping to move from broad reflection to concrete shared actions.

The two topics that received the highest level of support were working together to improve sunscreen access for lupus patients and creating a project around men's stories to raise awareness of lupus in men. Once these two priorities had been identified, the larger group split into two focused working groups.

The group working on sunscreen access focused on the need for stronger recognition of sunscreen as a genuine medical necessity for many people with lupus. The discussion highlighted that the cheapest sunscreen option is not always suitable, that awareness remains uneven among both patients and professionals, and that advice needs to be clearer and more visible for patients. Suggestions included linking the issue to EULAR recommendations, working towards recognition and reimbursement, encouraging stronger physician engagement, and developing a practical document that could support this work at European and national level.

The group working on men's stories focused on the need to find and amplify the voices of men living with lupus, both to reduce isolation and to challenge the persistent assumption that lupus is only or mainly a women's disease. Concrete next steps discussed included identifying a project lead and team, locating men through national groups, gathering stories in various formats including video, audio, written, or podcast-style, and ensuring representation of men of different ages and ethnicities.

This session was a strong example of the Convention's practical spirit. Rather than stopping at discussion, delegates worked together to identify priority areas and begin shaping realistic next steps that Lupus Europe and its National Members could tangibly work on together after the Convention.

Meet the Doctor

with Dr. Daniel Guimarães de Oliveira

The “Meet the Doctor” session offered delegates an open and engaging opportunity to ask questions directly to lupologist Dr. Daniel Guimarães de Oliveira in an informal and open setting. As in previous years, the session created space for participants to raise a wide range of questions linked to lupus, treatment, symptoms, and everyday management, and allowed for a very direct and practical exchange between the doctor and delegates.

The questions raised during the session reflected both clinical concerns and the lived realities of people with lupus. Topics discussed included kidney involvement in lupus, the reasons lupus nephritis is so common, weight gain linked to steroids and to reduced physical activity, the use of newer metabolic drugs, and the side effects and benefits of treatments such as hydroxychloroquine. Delegates also raised questions around flare recognition, fatigue, platelet changes, gastrointestinal and neurological symptoms, fungal infections, the long-term effects of steroids, and how doctors manage the complexity of multiple medications and comorbidities in lupus care.

A particularly important thread running through the discussion was the difficulty of defining and measuring some of the most meaningful patient experiences, especially fatigue and flare. Dr. Oliveira reflected on the limitations of existing clinical tools and scores, while also emphasising that from a practical point of view, what is important is when a patient feels significantly worse and that change is clinically meaningful enough to require attention.

The conversation also highlighted broader differences in care between countries. Delegates raised questions about access to treatment, national guidelines, and how lupus is managed in different healthcare systems. This led to reflections on the importance of national guidance, equitable access to treatment, and the need for continued progress so that improvements in lupus care can reach all patients in different countries across Europe.

RarERN Path and the Socioeconomic Burden of SLE

with Prof. Giuseppe Turchetti

The final morning began with a guest speaker session from Prof. Giuseppe Turchetti, Professor of Economics and Management at the Scuola Superiore Sant'Anna in Pisa, Italy, who introduced delegates to the concept of patient care pathways in rare diseases and to the work being developed within ERN ReCONNET. His presentation focused both on the RarERN Path methodology and on a related project exploring the socioeconomic burden of systemic lupus erythematosus (SLE), highlighting the importance of organisational thinking, patient voice, and real-world evidence in improving lupus care across Europe.

Prof. Turchetti began by explaining what a patient care pathway is and how it differs from concepts such as clinical guidelines or patient journeys. While guidelines describe what should be done clinically, a patient care pathway is an organisational tool that helps clarify who is involved, where care takes place, when different steps happen, and how the different parts of care are coordinated.

A central point of the presentation was that care pathways should not be designed by clinicians alone. Prof. Turchetti stressed that meaningful pathways must be co-designed by multiple stakeholders, including healthcare professionals, health economists, patient organisations, patients, and families, in order to capture the full range of barriers, expectations, and critical points that may arise across the pathway.

He then introduced the RarERN Path methodology, developed within ERN ReCONNET as a way of adapting the care pathway approach specifically to rare and complex diseases. This methodology includes several phases: mapping existing care pathways, collecting patient stories, designing an optimised pathway, validating it through stakeholder consensus, identifying indicators for monitoring and improvement, and eventually piloting and refining the pathway over time.

The second part of the session focused on the socioeconomic burden of SLE. Prof. Turchetti explained that this work aims to answer two major questions: what it means, from a socioeconomic point of view, to live with lupus in Europe, and what the overall burden is on healthcare systems, families, and society. He stressed that any serious understanding of lupus burden must go beyond direct medical costs alone and also include indirect costs such as work impact and caregiver burden, and intangible costs related to psychological and social impact and quality of life.

The session reinforced the importance of looking at lupus care not only in clinical terms, but also in organisational, social, and economic terms. It reinforced the idea that better pathways, better use of evidence, and stronger inclusion of patient experiences can all contribute to fairer, more effective, and more sustainable care for people living with lupus across Europe.

Message Tracks

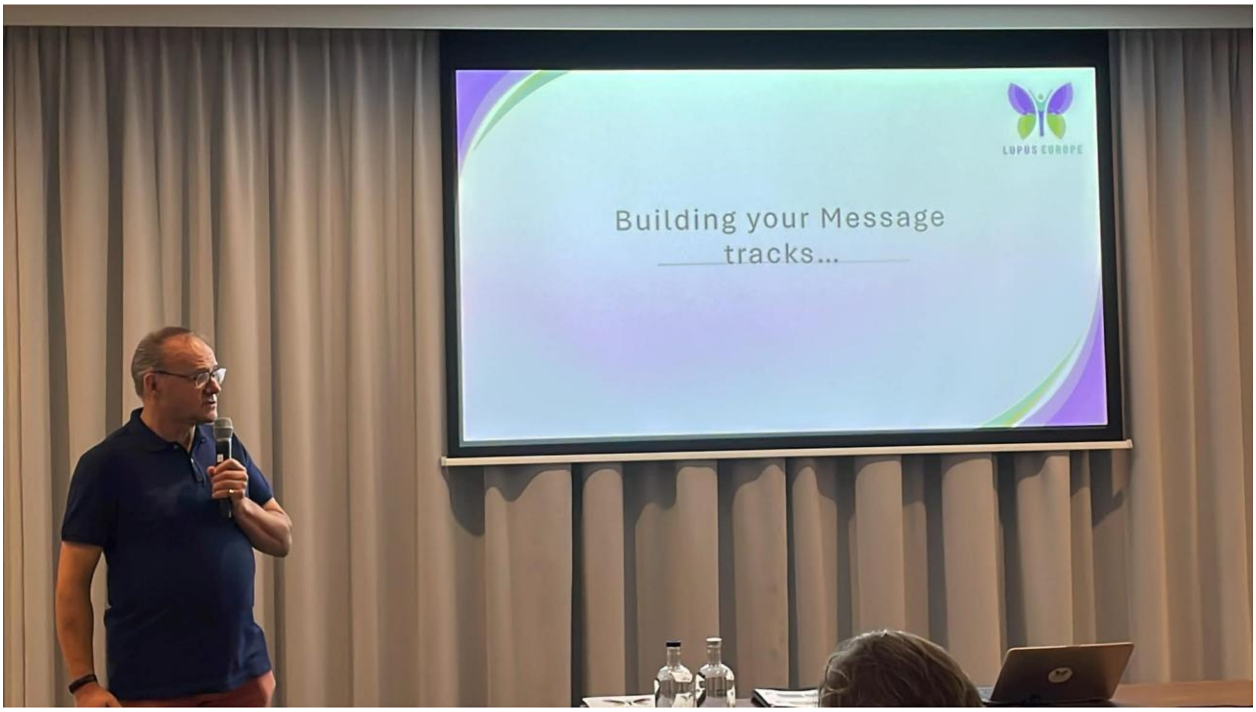
by Alain Cornet

Alain Cornet, Lupus Europe Organisation Coach & Finance Lead, led a practical and engaging session on message tracks, introducing delegates to a simple but effective tool for structuring communication more clearly and strategically. He explained that a message track helps speakers define a communication's desired core outcome. The emphasis throughout was on clarity, focus, and making communication simple and memorable rather than overloaded.

The session highlighted why message tracks are useful in practice: they help keep the speaker focused on what they want to say, help keep the audience focused on the most important points, and provide a practical and proven way to communicate more effectively, especially under pressure. Alain also presented a simple seven-step process for building a message track, moving from communication objective, to brainstorming and selecting key arguments, and then through validation, improvement, testing, alignment, and use.

Alain's presentation was followed by an interactive workshop-style exercise in small groups, where delegates worked on concrete message tracks linked to topics discussed during the Convention, including examples such as LupusGPT and other key themes. To support this practical work, Alain had also prepared printed triangle templates for delegates to use during the session and to take back to their National Groups afterwards.

This session gave participants a useful framework and an immediately usable practical tool to strengthen communication.



Closing

by Jeanette Andersen

The Convention closed on a warm and reflective note, bringing together the themes, discussions, and shared efforts of the previous days. Across the programme, delegates explored scientific developments, practical tools, advocacy priorities, patient experiences, organisational challenges, and new opportunities for collaboration. Together, these sessions once again showed the strength of the European lupus community when knowledge, experience, and commitment are shared openly.

This year's theme, "Every Voice Matters", was reflected throughout the Convention not only in the formal sessions, but also in the workshops, poster presentations, discussions, and exchanges between delegates. The Convention created space for many different voices to be heard, across countries, ages, experiences, and perspectives, and highlighted how much can be learned when our collective voices are brought together with openness and purpose.

In a particularly lovely addition to the Closing this year, Jeanette Andersen, Lupus Europe Chair, added butterflies to the collective tree that had been built throughout the Convention through the green Lupus Europe leaves and the yellow National Member leaves. These butterflies symbolised the possible synergies emerging from the Convention, as well as the new opportunities for shared work, collaboration, and collective action that had taken shape over the weekend. It was a powerful and hopeful visual reminder that the achievements already represented on the tree are not static but can continue to grow into new connections and future initiatives.

We hope delegates left the Convention not only with new knowledge and practical ideas, but also with renewed energy, stronger connections, and a sense of collective direction for the work ahead.

Glossary

PAN: Patient Advisory Network https://www.lupus-europe.org/pan

HTA: Health Technology Assessment

ERN ReCONNET: European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases https:/reconnet.ern-net.eu

SLE: Systemic Lupus Erythematosus

TRM-SLE: Treatment Response Measure – SLE https://www.monash.edu/medicine/scs/trm-sle/for-patients

LUPUS ALERT: SLE globAL contExt scReening Tool

EULAR: European Alliance of Associations for Rheumatology https://www.eular.org

Lupus100: Multi-lingual website with answers to the 100 lupus questions most commonly asked by patients https://lupus100.org

LupusGPT: Multi-lingual artificial intelligence tool providing valid, general information on lupus https://lupusgpt.org

EasyLupus: A feature of LupusGPT, providing multi-lingual, valid, general information on lupus in even easier language https://easy.lupusgpt.org

PFMD: Patient Focused Medicines Development https://patientfocusedmedicine.org