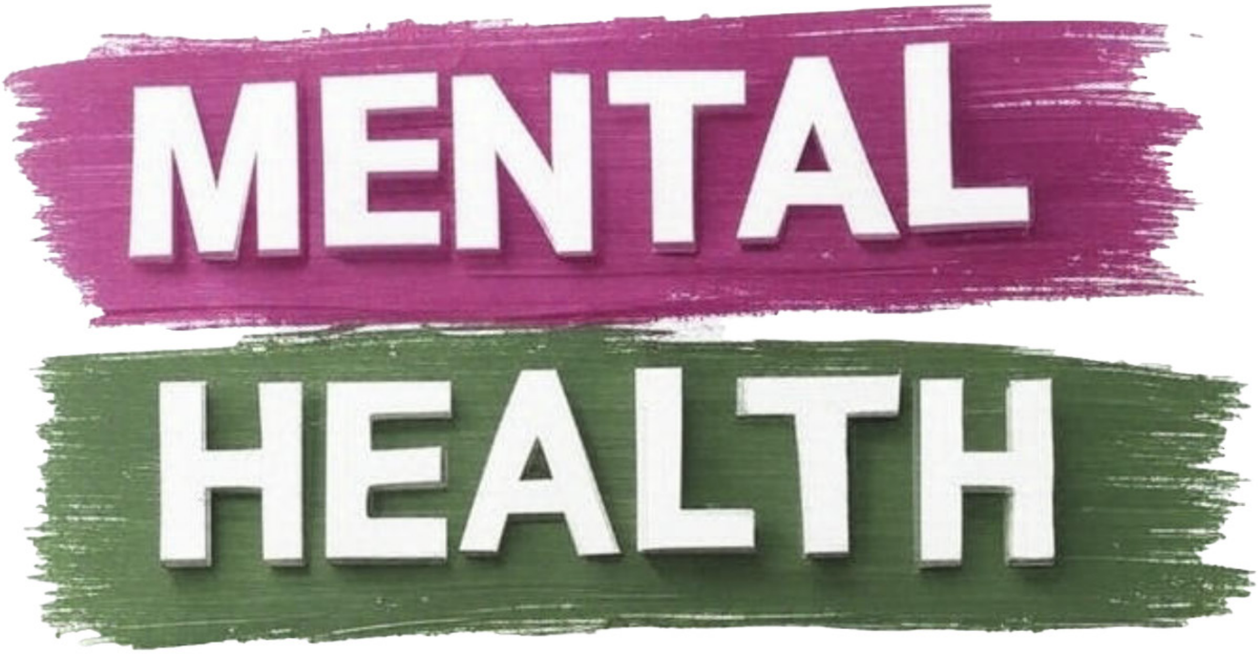
LUPUS EUROPE

# CONVENTION 2024

**Bratislava**, Slovakia19th **October** to 21st **October** 2024

report



# INDEX

# Introduction

The theme for Lupus Europe Annual Convention 2024 was “Mental Health”. Lupus is a systemic condition, but alongside physical symptoms the condition can have a significant psychological burden, particularly anxiety and depression. This can be detrimental to quality of life and can complicate disease management. Lupus Europe’s Living with Lupus in 2020 survey found that 1 in 2 lupus patients faces depression or anxiety, but these are undertreated, with more than 40% of respondents stating they do not have access to appropriate, professional psychologic support. Recognising the profound impact access to mental health support can have on quality of life for people with lupus and that collective thinking and concrete actions can be taken to work towards improving these issues for patients, the Convention focused on mental health.

**44 delegates** from **21 countries** and **7 industry partners** joined the Convention. **7 members of the Lupus Europe Youth Group** from 4 countries also 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*

The Yvonne Norton Grant

Through her tireless work and strong dedication Yvonne has helped shape Lupus Europe and created the foundation for the present organisation. That is why we in Lupus Europe have decided to create the Yvonne Norton Grant in loving memory of a very special person.
Each year, the Board of Lupus Europe will select a European lupus patient, who has made a positive difference for lupus patients and cannot otherwise afford the participation, and fund them to join our Annual Lupus Europe Convention. The grant will cover registration fee, travel, and accommodation for the entire Convention.
n in our hearts.

# Youth Group Day

## Pre-Convention Lupus Europe Youth Group Day

The Pre-Convention Lupus Europe Youth Group Day focused on interactive workshops and planning for the year. There were discussions on skincare, sex and sexual health, fertility, drug interactions, and mental and social health, all within the context of living with lupus.

Participants engaged in interactive discussions to come to a consensus on prioritising their tasks and deciding how to concretely move forward. The day also emphasised the value of accessible educational content, leading to plans for future webinars and podcasts on topics of importance. With a strong focus on peer support and expert insights, the Lupus Europe Youth Day provided valuable information, a chance to come together and work concretely on 2025 plans and a sense of belonging for young members.

## Youth Day – Bratislava

Being part of a Lupus Europe convention was an incredible and eye-opening experience! The youth group presents a unique opportunity for young people with lupus, and I want to highlight the aspects that resonate most with me. Firstly, I had the chance to volunteer and contribute to improving the lives of all individuals with lupus, regardless of their socio-economic or educational background.

Additionally, I connected with other young women who share similar challenges in their daily lives, and I've formed lasting friendships with some of them. The organization functions so effectively that we continue our meetings and work towards the goals we set during the convention, overcoming physical distance with determination. The youth day itself was enriching; we engaged in meaningful conversations, got to know one another deeply, and gained valuable insights about our disease.  Finally, the size of our group struck the perfect balance—not too crowded, yet not too small—enabling productive interactions and fostering personal relationships throughout the process.

I look forward to experiencing something like this again, filled with more ideas and impactful work!

Kind regards,
Leah Perivolaraki

# Men’s Day

## Men’s Day & Youth Group Kick-Off: Breaking the Silence

Ahead of the Lupus Europe Convention, we kicked off with two inspiring pre-event days: one dedicated to our younger members and another exclusively for men. With lupus affecting women in 9 out of 10 cases, men can often feel sidelined in their experiences. Together with Andreas Panteli from Lupus Switzerland, I co-organised a unique Men’s Day session, creating a safe space for open dialogue on topics rarely addressed in lupus groups.

Dr. Luis Perez from the Netherlands joined us, delivering an eye-opening presentation on sexual health challenges faced by men with lupus. His interactive Q&A tackled tough issues—mental health stigma, daily hurdles, and more—with men’s day participants praising the rare opportunity to speak freely without judgment. The day ended on a warm note with a traditional Slovakian meal, fostering connection and camaraderie.

At the same time, the Lupus Europe Youth Group launched their meeting with vibrant energy, setting the stage for 2025. Through workshops unpacking the complexities of lupus and engaging strategy games, our young advocates sparked fresh ideas and showcased the vital role of youth in driving change across Europe.

## **Youth Day** – Bratislava

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# Opening Session

Jeanette Andersen (Chair - Lupus Europe) welcomed all participants, as well as the industry guests that joined us for the first day of the Convention. For our Youth Group, this was already the 2nd day of meeting as they met on the Friday for a full day, to share their progress, to discuss issues of common interest and to make concrete plans for 2025.

The Opening Session began with a heartfelt tribute to Yvonne Norton, whose dedication to the lupus community will always be remembered. The newly established Yvonne Norton Grant, named in her honour, will annually fund the participation to the Lupus Europe Annual Convention of a lupus patient, living in Europe, who has made a significant positive impact to the community but would otherwise be unable to attend. The grant provides the recipient with full coverage for registration, travel, and accommodation.

This year’s recipient, Pilar Álvarez Siles, was recognised for her lifelong work in supporting lupus patients in Spain, including her co-founding of FELUPUS and her continued leadership in the Lupus Cádiz association.

Delegates were welcomed and introduced themselves one by one, sharing their names, countries and organisations. Jeanette then shared the full agenda of the Convention, where workshops on mental health were important components, and also introduced the current year Convention theme “Mental Health”, setting the stage for engaging discussions and workshops so we can look for creative solutions on a topic of interest for so many people with lupus!

LUPUS EUROPE

Annual Lupus Europe Convention 2024

# Lupus and Mental Health

### by Dr. Chris Wincup

Dr. Chris Wincup, Consultant Rheumatologist at King's College Hospital, London, delivered a session on mental health and lupus, touching also on neuropsychiatric lupus (NPSLE), and emphasising the complexities and impact on lupus patients of mental health difficulties and NPSLE. Dr. Wincup introduced the session with an exploration of the intricate nature of the brain and nervous system, noting that damage in this area can be difficult to repair. This highlights the challenge of understanding and treating neuropsychiatric symptoms in systemic lupus erythematosus (SLE), where, according to Dr. Wincup, both direct inflammation and the effects of treatments can sometimes complicate diagnosis and care.

Dr. Wincup presented several case studies to illustrate the challenges faced by patients and clinicians. It remains challenging to determine whether neuropsychiatric symptoms may be due to the disease itself, some of the medications sometimes used for treatment (such as high dose steroids), or concurrent psychiatric conditions. The session highlighted the difficulty that can exist in identifying the underlying causes of these symptoms and stressed the importance of early recognition and open discussions with physicians about them. Dr. Wincup highlighted that neuropsychiatric symptoms can often go underrecognised, but that it is incredibly important for patients to raise the topic with their doctor if they are experiencing neurological or psychological symptoms of any kind.

The presentation also covered the frequency of neurological and mental health symptoms in lupus, pointing out that difficulties in those domains for people can range from tremors and visual changes to sensory disturbances or alterations in mood such as depression and anxiety. Dr. Wincup shared findings from studies showing that while these symptoms can significantly impact the daily lives of lupus patients, they are often overlooked, with many patients failing to receive the mental health support they need.

The session concluded with a call for better tools and approaches to identify and treat neurological and psychological symptoms in lupus. Dr. Wincup recommended a multidisciplinary team approach that includes psychiatrists, psychologists, and any other relevant specialists to address complex symptoms if and when they arise. He emphasised the need for more research into biomarkers for these kinds of lupus symptoms and talked about potential, future uses of technology, such as symptom tracking apps and remote monitoring, to improve patient care. Dr. Wincup emphasised there is a need for increased awareness among clinicians regarding these kinds of symptoms. Finding ways to better identify and discuss these symptoms in consultations was brought up; the ASK, TELL, have an honest conversation, acknowledge model was covered as a potential solution. Under this model clinicians should aim to ask patients directly about their mental health, patients should aim to be honest with their clinicians about any mental health concerns or symptoms they may be experiencing. Having an honest conversation about it in consultation and acknowledging the difficulties can pave the way to better addressing these concerns early and to further improving the quality of life and treatment outcomes for people living with lupus.

# Mental Health Workshop A

Mental health is a critical but often overlooked aspect of holistic lupus care. According to the Living with Lupus in 2020 survey, 1 out of 2 lupus patients faces depression or anxiety, but is undertreated for it. Out of those who have stated they have depression or anxiety, 40% said they had no access to professional psychological support. In fact, only 22% of respondents said they did have access to professional psychological support.

Access inequalities across countries are notable; this is no different when it comes to mental health. We also know, from the Mental Health Patient Panel that took place in 2024, that when it comes to mental health in lupus, doctor/patient communication plays a significant part in peoples' experiences.

This session was an interactive workshop focused on unearthing barriers to accessing mental health support for lupus patients, exploring communication challenges between patients and doctors, and considering steps patient groups could take to improve the mental health situation of people living with lupus.

The workshop highlighted patients often face significant challenges when communicating about mental health with their doctors. It was noted that patients do not always feel comfortable speaking up about mental health concerns, leading to undertreatment or insufficient care. Communication gaps were identified, with patients expressing a lack of space to talk openly about their mental health with specialist lupus doctors.

A number of barriers to accessing mental health support were raised, including long waiting times to access support from mental health professionals like psychologists or psychiatrists, limited availability of psychological support in some countries and lack of referral systems, where specialists are not able to refer lupus patients for psychological support unless they have more severe physical symptoms like nephritis. Funding and private healthcare issues were raised as well with patients having to pay out of pocket for psychological support, further exacerbating access inequalities.

A key discussion point was the absence of specialised mental health care for lupus patients. In many countries, lupus care does not include mental health, and patients are often left to navigate the mental health system without proper support. This includes the absence of trained mental health professionals within lupus clinics, and it is exacerbated by the stigma surrounding mental health issues in some communities.

Possible solutions for patient groups that were discussed included training for healthcare professionals to help them identify and address mental health concerns in lupus patients and move towards a more integrated care model. The need for safe spaces for mental health conversations was also discussed. Patients need safe, supportive environments where they can freely talk about their mental health without fear of judgment. The role of patient groups in providing resources and peer support to patients was also mentioned. This included raising awareness and advocating for better resources for mental health care.

Delegates were then asked about their ideal mental health support structures for lupus patients. They envisioned systems where mental health care was integrated into lupus care, providing seamless support alongside physical health care. They also discussed the importance of confidentiality and personalised care for patients seeking help. One of the suggestions was that lupus groups could collaborate with mental health organisations to create better referral systems for mental health care and provide financial support to make these services more accessible. One of the points raised was that national lupus groups could create educational materials to guide lupus patients on how to seek help for mental health issues, including how to navigate referral processes and find financial support.

Another idea was that lupus patient groups could partner with psychologists, counsellors, and other mental health specialists to develop workshops, support groups, and informational sessions for lupus patients.This session provided a crucial opportunity to explore the systemic issues impacting mental health care for lupus patients. While patients face many barriers in accessing mental health support, there was a strong belief that patient groups can play a key role in improving the mental health support for people living with lupus in Europe.

LUPUS EUROPE

# Strategic Plan Game

The Lupus Europe Strategic Plan Game was not only an exciting and interactive experience but also a crucial opportunity to engage national delegates with the organisation's strategic plan for 2023-2028 and its strategic priorities. The treasure hunt format encouraged teams of delegates to explore Bratislava while deepening their understanding of Lupus Europe's initiatives, such as LupusGPT, the Lupus100 project, and key research initiatives. However, the true value of the event lay in how it also sparked fresh, creative ideas and provided meaningful feedback on the organisation's current and possible future strategies.

As each team of participants moved from stop to stop, they were met by a member of the Board or extended Board, each of them stationed at key points of historical significance around the city. They guided the teams through the various challenges, providing clues for the next round and engaging in discussions while each team presented answers from questions received at the previous stop. As teams progressed through the city, they collected puzzle pieces and answered questions on the organisation's work and brainstormed. Many participants came up with innovative ideas for possible future campaigns and initiatives, from new ways to break down language barriers to possible new campaigns for mental health and lupus. The game format facilitated teamwork, open dialogue and critical thinking, allowing participants to share their thoughts on areas of focus for the future, including potential themes for upcoming conventions and ideas for expanding Lupus Europe's outreach efforts.

The game successfully blended strategic discussions with fun, a bit of sightseeing and exercise, and provided a platform for creative brainstorming that helped get ideas for and feedback on the direction of Lupus Europe's initiatives. When all questions were answered and all puzzle pieces were collected, delegates returned to the hotel. There, the next task was to put the puzzle together – each puzzle representing the Lupus Europe strategic plan illustration. Each participant received a complete puzzle to take home, allowing them to share the strategic vision and plan with their National Group and further engage their members in the ongoing conversation about Lupus Europe's future direction. By the end of the game, participants not only deepened their understanding of Lupus Europe's strategic plan but also actively contributed to the organisation's strategic vision, making the event both a celebration and a valuable source of insight for the organisation's future.

# **Poster** Tour

The poster session was a wonderful way for our delegates to share something they have done in the past year in their National Groups with us all.

Lupus France shared an informative poster highlighting a variety of initiatives, including a collection of testimonies from patients, doctor and family members of people with lupus and the participation of their President in the "Raid des Alizés" to raise awareness for lupus.

## LUPUS FRANCE - PROJETS

### LE LUPUS
### 100 QUESTIONS

QUESTIONS-RÉPONSES AVEC DES SPÉCIALISTES DES CENTRES DE RÉFÉRENCE

### VIDÉO
### DE SENSIBILISATION

SUR LES IMPACTS AU QUOTIDIEN
POUR UN MALADE DU LUPUS

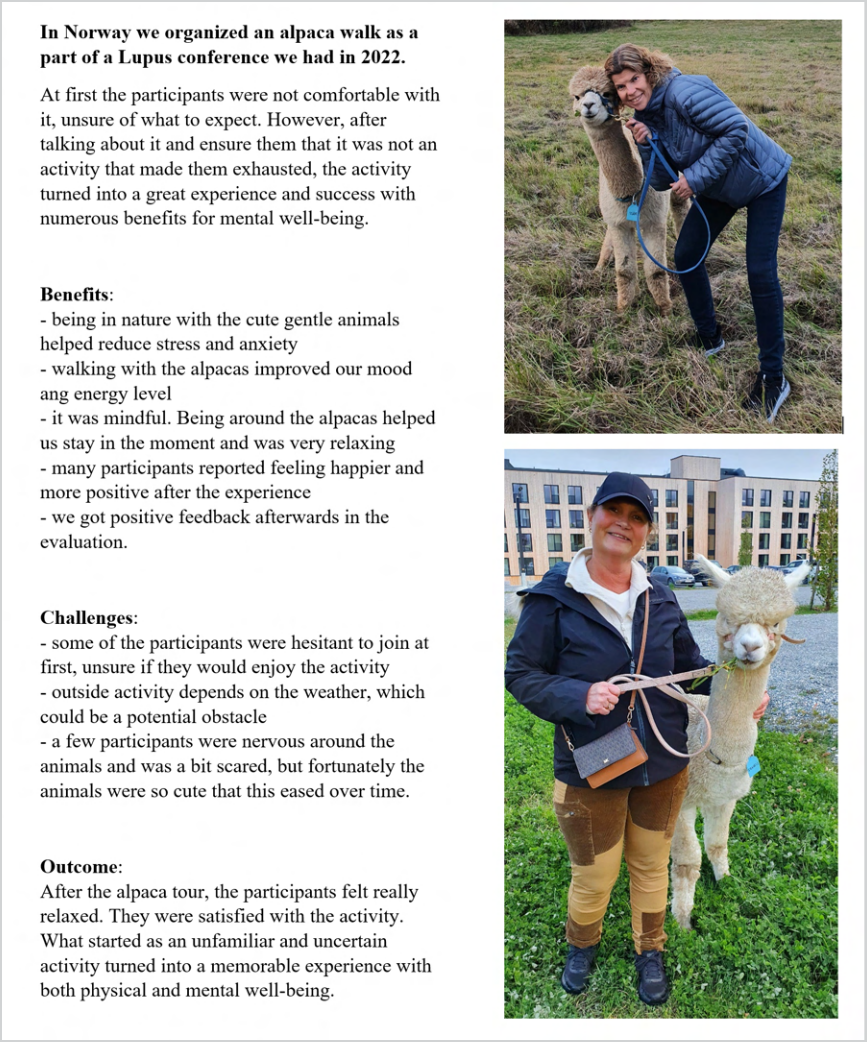
### TÉMOIGNAGES
### NOS VIES AVEC LE LUPUS

RECUEIL DE TÉMOIGNAGES DE MALADES, PARENTS, AMIS, FAMILLES & MÉDECINS

### LES LOUVES DE CAHU
### AU RAID DES ALIZÉS

LA PRÉSIDENTE DE LUPUS FRANCE
PRÉPARE LE RAID DES ALIZÉS

Lupus Norway shared a heartwarming poster detailing their successful Alpaca Walk event, which was part of a lupus conference in 2022, where participants reported reduced stress, improved mood, and increased relaxation from interacting with the gentle animals.



**In Norway we organized an alpaca walk as a part of a Lupus conference we had in 2022.**

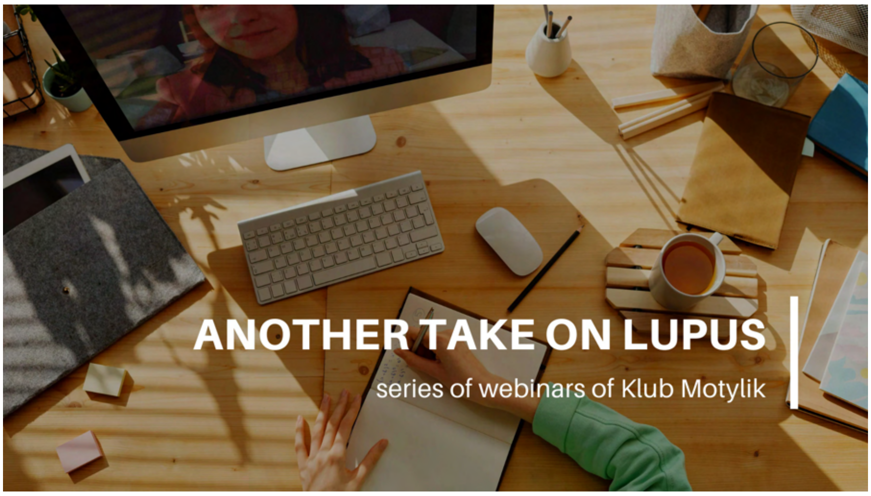
At first the participants were not comfortable with it, unsure of what to expect. However, after talking about it and ensure them that it was not an activity that made them exhausted, the activity turned into a great experience and success with numerous benefits for mental well-being.

**Benefits**:
- being in nature with the cute gentle animals helped reduce stress and anxiety
- walking with the alpacas improved our mood ang energy level
- it was mindful. Being around the alpacas helped us stay in the moment and was very relaxing
- many participants reported feeling happier and more positive after the experience
- we got positive feedback afterwards in the evaluation.

**Challenges**:
- some of the participants were hesitant to join at first, unsure if they would enjoy the activity
- outside activity depends on the weather, which could be a potential obstacle
- a few participants were nervous around the animals and was a bit scared, but fortunately the animals were so cute that this eased over time.

**Outcome**:
After the alpaca tour, the participants felt really relaxed. They were satisfied with the activity. What started as an unfamiliar and uncertain activity turned into a memorable experience with both physical and mental well-being.

Klub Motylik (Slovakia) shared an engaging poster highlighting their "Another Take on Lupus" webinar series, which focused on offering fresh perspectives and information about lupus to the community through accessible online sessions.



NVLE (the Netherlands) shared two insightful posters: one focused on their 5-year plan (2022-2027) to reach out to patients from diverse backgrounds, and the other featured a congress on diversity and inclusion with a focus on how delayed diagnoses affect patients with dark skin.

Nationale vereniging voor mensen met
Lupus, APS, sclerodermie en MCTD

**Informatiemiddag SLE en Huidlupus**
door dokters uit
het Maasstad ziekenhuis en het Erasmus MC

**Wanneer:** Zaterdag 7 december '24
**Waar:** Huis van de Wijk Millinxparkhuis
Millinxstraat 69, 3081 PE Rotterdam
**Hoe laat:** van 12.30-17.00 uur

**Meld je nu aan, toegang is gratis**
Bel: **088-0157070** op werkdagen van 13.00-17.00 uur
Mail: richmonde@nvle.org
Scan: **de QR-code.**
Schrijf: **secretariaat NVLE**
antwoordnummer 4143, 3500 VB Utrecht.
Via de site van de NVLE: www.nvle.org/aanmelden-7-december
In het hoofdmenu vind je onder het kopje 'Nieuws' de bijeenkomsten

Geef je **naam** en **e-mailadres** door.
Met **hoeveel personen** kom je?
Maak je gebruik van **een rolstoel?**
Ben je **lid van de NVLE?**
Heb je een vraag, stel hem in de mail.

12.30 uur **Inloop met koffie en thee**
13.00 uur **Welkomstwoord**
13.05 uur **Huidproblematiek bij SLE en Huidlupus**
Dr. E.J.M. Zirkzee, Reumatoloog Maasstad ziekenhuis
13.50 uur **Haarproblemen en mogelijke oplossingen**
Romy Hoppenbrouwers, Fleum Haarstudio
14.05 uur **Pauze** met koffie, thee en wat lekkers
14.35 uur **Mijn leven met SLE**
Patricia Kim
14.50 uur **Zwangerschap bij SLE**
Dr. L.F. Perez, Reumatoloog Erasmus MC
Dr R.J.E.M. Dolhain, Reumatoloog Erasmus MC
15.35 uur **Wat kan de NVLE voor u betekenen?**
Richmonde van Daalen, Vrijwilliger NVLE
16.00 uur **Lotgenotencontact** met een drankje en een hapje
17.00 uur **Afsluiting**

Vanaf 16.00 uur kunnen we met elkaar praten over ons leven met SLE en Huidlupus en genieten van een fris drankje en lekkere hapjes zoals; bladerdeegflapjes met spinazie en feta, maiskoekjes, pasteitjes met erwtjes en peen, Afrikaanse gehaktballetje en Vietnamese loempiaatjes. We zien je graag op 7 december.

Nationale vereniging voor mensen met
lupus, APS, sclerodermie en MCTD

**5-year plans 2022-2027 of our patient organization: reach out to patients with other backgrounds.**

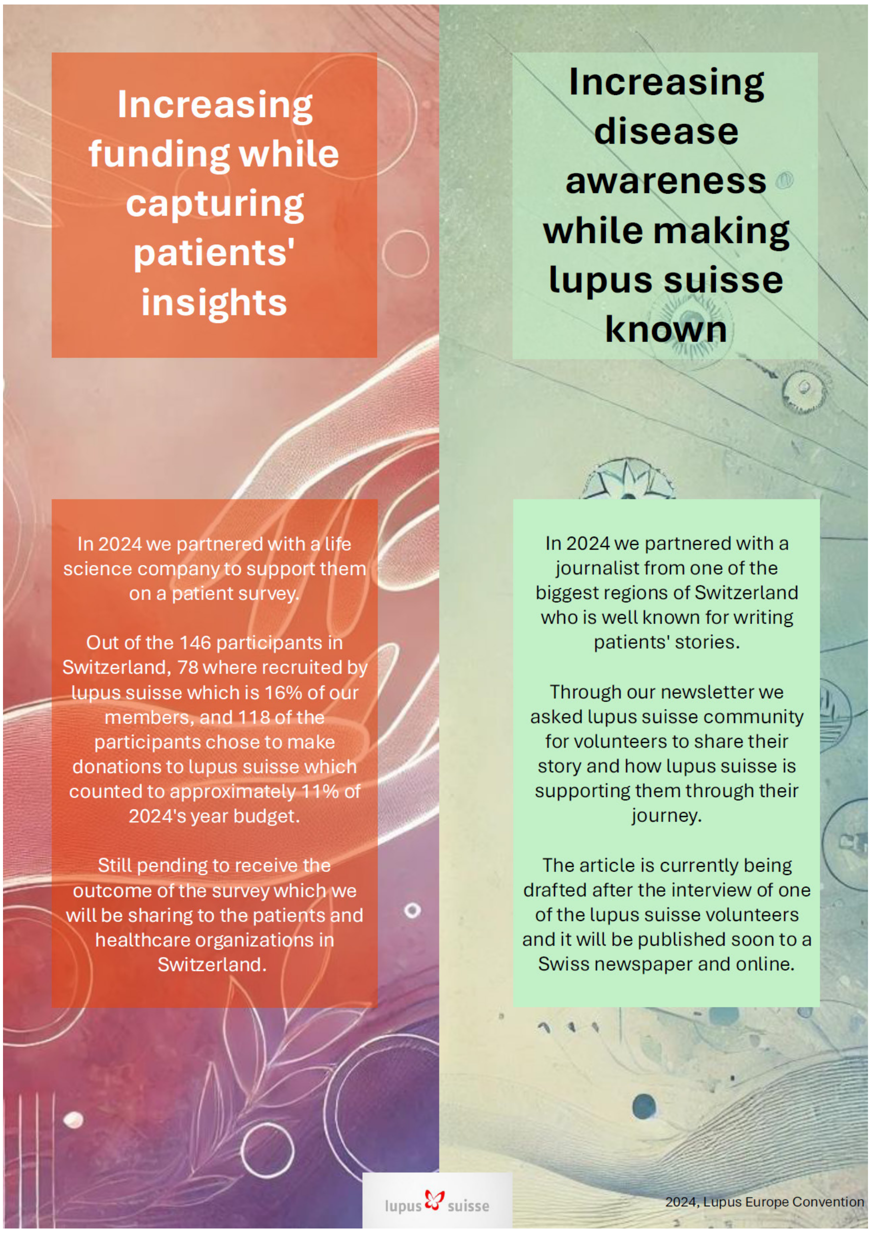
Ernstiger beloop op basis van ras/etniciteit?

Kallas et al. J Rheumatol 2022

9 December 2023 we organized **a meeting** in Amsterdam (South-East) specifically for a diverse public that lives there. Irene Bultink and Marc Hillhorst, doctors in our Medical Advisory Board invited their patients and spoke at the meeting. At least 2/3rd of the public was **not** a member of the NVLE.
People with a dark skin have a **delayed diagnose** compared to white patients. Most books for students have pictures of white people in them.

The 29th of June we held a congress where speaker Michel Tjan-a-Sjoe talked about diversity and inclusion. Kallas et al. J Rheumatology 2022, with correction on financial status the total Damage Index of Blacks is greater than for Whites.

Lupus Suisse shared an impactful poster detailing their 2024 initiatives, including a partnership with a journalist to collect and highlight patient stories and a partnership with a life science company to support them on a patient survey.



## Increasing funding while capturing patients' insights

In 2024 we partnered with a life science company to support them on a patient survey.

Out of the 146 participants in Switzerland, 78 where recruited by lupus suisse which is 16% of our members, and 118 of the participants chose to make donations to lupus suisse which counted to approximately 11% of 2024's year budget.

Still pending to receive the outcome of the survey which we will be sharing to the patients and healthcare organizations in Switzerland.

## Increasing disease awareness while making lupus suisse known

In 2024 we partnered with a journalist from one of the biggest regions of Switzerland who is well known for writing patients' stories.

Through our newsletter we asked lupus suisse community for volunteers to share their story and how lupus suisse is supporting them through their journey.

The article is currently being drafted after the interview of one of the lupus suisse volunteers and it will be published soon to a Swiss newspaper and online.

2024, Lupus Europe Convention

The Lupus Group of RRA Nadezhda (Russia) shared an interesting poster focusing on mental health and lupus, and that included a self-care guide that includes strategies, nutrition advice, exercise routines, UV protection tips, and meditation techniques.

LUPUS EUROPE

**Lupus & Mental Health:**
dedicated activities in Russia in 2023/24

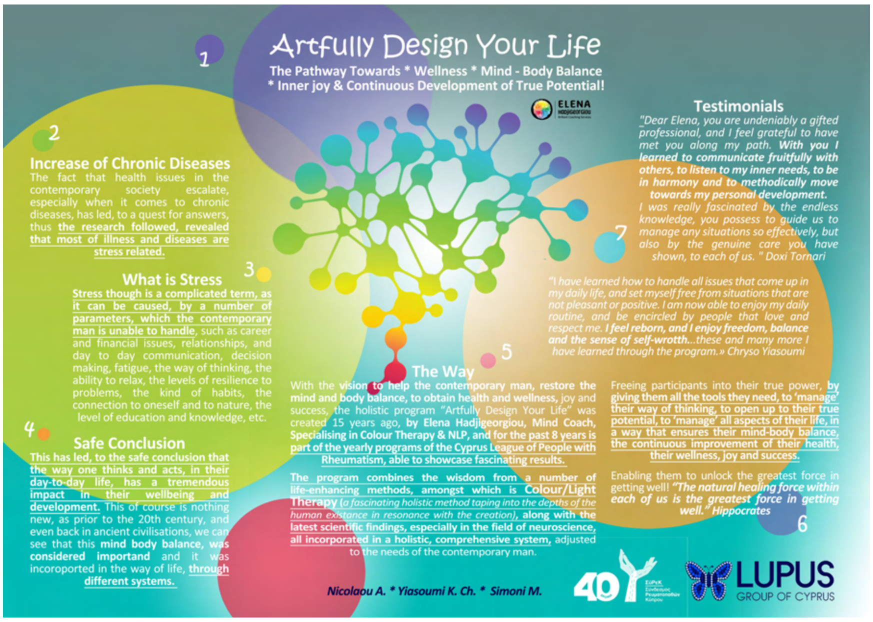
**Interview with a practicing psychologist:**

Lupus patient asking questions collected in patient society regarding mental burden of the disease, coping mechanisms and support services available to patients in Russia.

**Self-care project "Energy of Life" for Lupus patients**

Including self-help and nutrition guide along with 5 different exercise routines developed by a major fitness platform specifically for Lupus patients and recorded with members of PAG "Nadezhda". The guide also includes other tips for patients such as UV-protection, enhancing quality of sleep, dealing with disease exacerbation, meditation techniques etc.

CYPLER (Cyprus) shared an inspiring poster titled "Artfully Design Your Life," showcasing a holistic program aimed at restoring mind-body balance and promoting wellness through stress management, colour-light therapy and self-care practices, with testimonials highlighting the programme's impact on peoples' lives.



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## Artfully Design Your Life

**The Pathway Towards * Wellness * Mind - Body Balance**
*** Inner joy & Continuous Development of True Potential!**

ELENA HADJIGEORGIOU

2

### Increase of Chronic Diseases

The fact that health issues in the contemporary society escalate, especially when it comes to chronic diseases, has led, to a quest for answers, thus **the research followed, revealed that most of illness and diseases are stress related.**

3

### What is Stress

**Stress though is a complicated term, as it can be caused, by a number of parameters, which the contemporary man is unable to handle**, such as career and financial issues, relationships, and day to day communication, decision making, fatigue, the way of thinking, the ability to relax, the levels of resilience to problems, the kind of habits, the connection to oneself and to nature, the level of education and knowledge, etc.

4

### Safe Conclusion

**This has led, to the safe conclusion that the way one thinks and acts, in their day-to-day life, has a tremendous impact in their wellbeing and development.** This of course is nothing new, as prior to the 20th century, and even back in ancient civilisations, we can see that this **mind body balance, was considered importand** and it was incoroported in the way of life, **through different systems.**

5

### The Way

With the **vision to help the contemporary man, restore the mind and body balance, to obtain health and wellness,** joy and success, the holistic program "Artfully Design Your Life" was created 15 years ago, **by Elena Hadjigeorgiou, Mind Coach, Specialising in Colour Therapy & NLP, and for the past 8 years is part of the yearly programs of the Cyprus League of People with Rheumatism, able to showcase fascinating results.**

**The program combines the wisdom from a number of life-enhancing methods, amongst which is Colour/Light Therapy** (*a fascinating holistic method taping into the depths of the human existance in resonance with the creation)*, **along with the latest scientific findings, especially in the field of neuroscience, all incorporated in a holistic, comprehensive system,** adjusted to the needs of the contemporary man.

6

Freeing participants into their true power, **by giving them all the tools they need, to 'manage' their way of thinking, to open up to their true potential, to 'manage' all aspects of their life, in a way that ensures their mind-body balance, the continuous improvement of their health, their wellness, joy and success.**

Enabling them to unlock the greatest force in getting well! ***"The natural healing force within each of us is the greatest force in getting well." Hippocrates***

7

### Testimonials

*"Dear Elena, you are undeniably a gifted professional, and I feel grateful to have met you along my path.* ***With you I learned to communicate fruitfully with others, to listen to my inner needs, to be in harmony and to methodically move towards my personal development.***
*I was really fascinated by the endless knowledge, you possess to guide us to manage any situations so effectively, but also by the genuine care you have shown, to each of us. " Doxi Tornari*

*"I have learned how to handle all issues that come up in my daily life, and set myself free from situations that are not pleasant or positive. I am now able to enjoy my daily routine, and be encircled by people that love and respect me.* ***I feel reborn, and I enjoy freedom, balance and the sense of self-wrotth…****these and many more I have learned through the program.» Chryso Yiasoumi*

***Nicolaou A. * Yiasoumi K. Ch. * Simoni M.***

40 ΣυΡεΚ Σύνδεσμος Ρευματοπαθών Κύπρου

LUPUS GROUP OF CYPRUS

Lupus Belgium shared an engaging poster that included their participation in World Lupus Day, their recent publication of two lupus-focused magazines, a website redesign, and a successful annual day with expert talks and a 5-kilometer walk.

This year, the Belgian association "Lupus Erythémateux" participated in AstraZeneca's campaign for World Lupus Day. During this campaign, two of our members were filmed: one provided a video testimonial, while the other participated in an "holobox" experience. In the holobox, visitors can select a question, and the filmed member responds, fostering greater understanding and awareness of lupus.

L'association Lupus vous accompagne au quotidien.

We also published two magazines to inform our members about lupus. Currently, we are revamping our website to modernize its design and update its content.

Finally, on Saturday, October 5th, we held our annual day, featuring two speakers who discussed the relationship between hormones and lupus, as well as the different forms of cutaneous lupus.
We concluded the day with a 5-kilometer walk, because as everyone knows, staying active is important for lupus patients.

Association Lupus Erythémateux

Lupus Italy shared an extensive poster showcasing their ongoing initiatives to raise awareness and provide support for lupus patients, including monthly live broadcasts with specialists and participation in World Lupus Day activities. They also highlighted their involvement in significant research projects and their continuous efforts to support lupus clinics across Italy.

Gruppo
LES
Italiano
ODV

## *Lupus Italy*

We keep providing patients with assistance, up-to-date information about Lupus and new therapies, to increase patients' awareness of their rights.

We continue our live broadcast service started in April 2020.
In these live broadcasts we host specialists who talk about different topics suggested and chosen by patients, and answer to patients' questions trying to clear up all their doubts.
We keep broadcasting these live events once a month.

At the same time we regularly keep posting on our social networks video interviews with Italian Lupus specialists on different topics.

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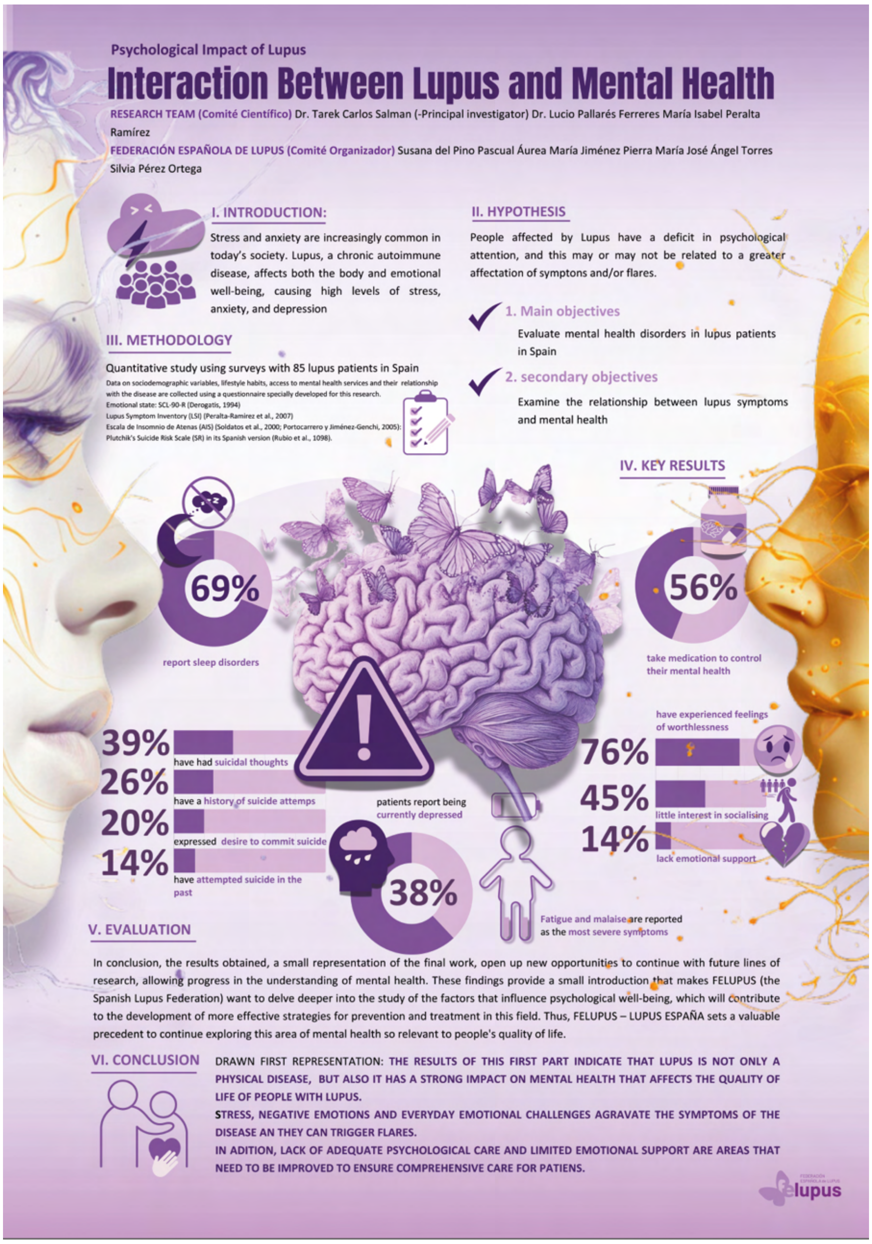
Every year we celebrate **'World Lupus Day - May 10th'** and the whole month is devoted to raising public awareness about Lupus.

World Lupus Day 2024 was very successful in all of Italy: we participated in press conferences, our commercial was shown on regional television, posters were put up in pharmacies, we held doctor-patient regional meetings as well as press conferences, and we distributed "Sunflowers" for fundraising . . .

FELUPUS (Spain) shared an informative poster exploring the interaction between lupus and mental health, presenting the results of a study with 85 lupus patients in Spain. This study highlighted high levels of mental health related symptoms, as well as a need for improved psychological care for people with lupus who also have mental health difficulties.



Psychological Impact of Lupus

## Interaction Between Lupus and Mental Health

**RESEARCH TEAM (Comité Científico)** Dr. Tarek Carlos Salman (-Principal investigator) Dr. Lucio Pallarés Ferreres María Isabel Peralta Ramírez

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### I. INTRODUCTION:

Stress and anxiety are increasingly common in today's society. Lupus, a chronic autoimmune disease, affects both the body and emotional well-being, causing high levels of stress, anxiety, and depression

### II. HYPOTHESIS

People affected by Lupus have a deficit in psychological attention, and this may or may not be related to a greater affectation of symptons and/or flares.

✓ 1. Main objectives

Evaluate mental health disorders in lupus patients in Spain

✓ 2. secondary objectives

Examine the relationship between lupus symptoms and mental health

### III. METHODOLOGY

Quantitative study using surveys with 85 lupus patients in Spain

Data on sociodemographic variables, lifestyle habits, access to mental health services and their relationship with the disease are collected using a questionnaire specially developed for this research.
Emotional state: SCL-90-R (Derogatis, 1994)
Lupus Symptom Inventory (LSI) (Peralta-Ramirez et al., 2007)
Escala de Insomnio de Atenas (AIS) (Soldatos et al., 2000; Portocarrero y Jiménez-Genchi, 2005):
Plutchik's Suicide Risk Scale (SR) in its Spanish version (Rubio et al., 1098).

### IV. KEY RESULTS

69% report sleep disorders

56% take medication to control their mental health

39% have had suicidal thoughts

26% have a history of suicide attemps

20% expressed desire to commit suicide

14% have attempted suicide in the past

38% patients report being currently depressed

76% have experienced feelings of worthlessness

45% little interest in socialising

14% lack emotional support

Fatigue and malaise are reported as the most severe symptoms

### V. EVALUATION

In conclusion, the results obtained, a small representation of the final work, open up new opportunities to continue with future lines of research, allowing progress in the understanding of mental health. These findings provide a small introduction that makes FELUPUS (the Spanish Lupus Federation) want to delve deeper into the study of the factors that influence psychological well-being, which will contribute to the development of more effective strategies for prevention and treatment in this field. Thus, FELUPUS – LUPUS ESPAÑA sets a valuable precedent to continue exploring this area of mental health so relevant to people's quality of life.

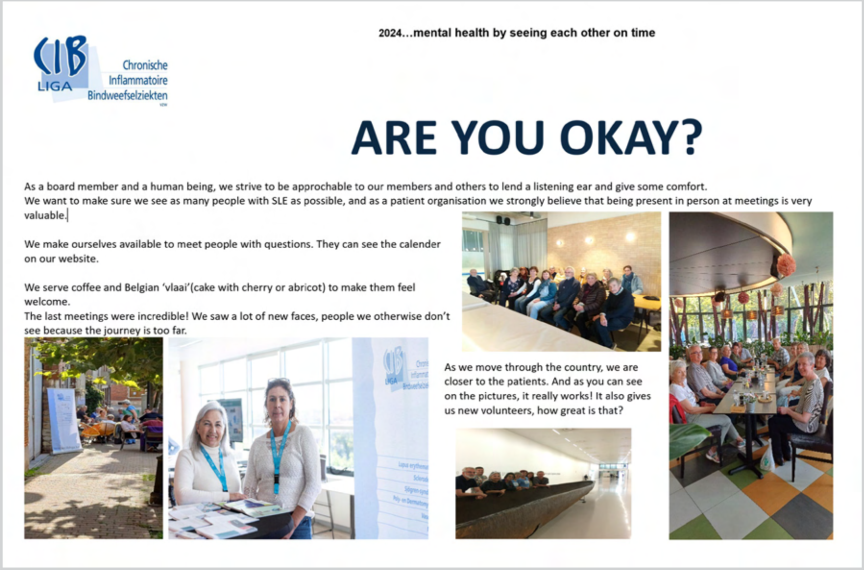
### VI. CONCLUSION

DRAWN FIRST REPRESENTATION: THE RESULTS OF THIS FIRST PART INDICATE THAT LUPUS IS NOT ONLY A PHYSICAL DISEASE, BUT ALSO IT HAS A STRONG IMPACT ON MENTAL HEALTH THAT AFFECTS THE QUALITY OF LIFE OF PEOPLE WITH LUPUS.

STRESS, NEGATIVE EMOTIONS AND EVERYDAY EMOTIONAL CHALLENGES AGRAVATE THE SYMPTOMS OF THE DISEASE AN THEY CAN TRIGGER FLARES.

IN ADITION, LACK OF ADEQUATE PSYCHOLOGICAL CARE AND LIMITED EMOTIONAL SUPPORT ARE AREAS THAT NEED TO BE IMPROVED TO ENSURE COMPREHENSIVE CARE FOR PATIENS.

CIB Liga (Belgium) shared a wonderful poster titled "Are You Okay?", detailing their efforts to connect with lupus patients through in-person meetings, where they provide a welcoming environment with coffee and Belgian "vlaai" to foster comfort and engagement, while expanding their outreach across the country and gaining new volunteers.



2024...mental health by seeing each other on time

CIB LIGA
Chronische
Inflammatoire
Bindweefselziekten

# ARE YOU OKAY?

As a board member and a human being, we strive to be approchable to our members and others to lend a listening ear and give some comfort.
We want to make sure we see as many people with SLE as possible, and as a patient organisation we strongly believe that being present in person at meetings is very valuable.

We make ourselves available to meet people with questions. They can see the calender on our website.

We serve coffee and Belgian 'vlaai'(cake with cherry or abricot) to make them feel welcome.
The last meetings were incredible! We saw a lot of new faces, people we otherwise don't see because the journey is too far.

As we move through the country, we are closer to the patients. And as you can see on the pictures, it really works! It also gives us new volunteers, how great is that?

# Lupus & Mental Health from a Young Doctor's Perspective

### by Luca Moroni

As in the previous year we also opened up for young doctors to apply to take part in this year´s Convention. Dr. Luca Moroni from Italy was selected to join the Convention as a young doctor specialising in lupus and ran a session for delegates on lupus and mental health from the doctor's perspective. The session delved into the critical intersection of lupus and mental health, highlighting the significant impact lupus can have on both psychological well-being and the quality of life of patients. Dr. Moroni's presentation emphasised that mental health issues in lupus patients are often overlooked, yet they are highly prevalent and directly influence disease management.

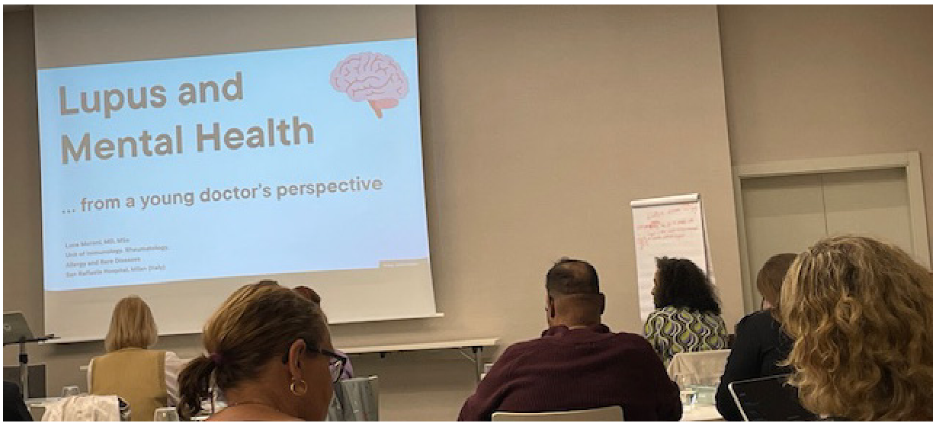
Key findings shared during the session illustrated the complex relationship between lupus and mental health. Anxiety and depression are notably common, affecting approximately 25% and 37% of lupus patients, respectively. This finding is congruent with Lupus Europe's Living with Lupus in 2020 survey, which revealed that 43.6% of respondents regularly experience depression or anxiety, and highlights the mental health challenges often faced by people living with lupus.

Patients with lupus have a significantly higher likelihood of experiencing severe depression compared to healthy controls. These mental health challenges may sometimes be compounded by neuropsychiatric lupus (NPSLE), a condition where lupus-related inflammation affects the brain.

Dr. Moroni also touched on the role of trauma, highlighting a study that found 31% of lupus patients participating had PTSD, profoundly impacting their quality of life. Alexithymia, or the inability to describe and express emotions, was also discussed, and was noted to have a significant prevalence in lupus patients. The presentation brought attention to the connection between trauma and the onset of lupus, suggesting that trauma exposure could possibly be associated with a slight increase in the risk of developing the disease.

The importance of treating mental health issues in lupus patients was emphasised, as untreated psychological distress can hinder treatment adherence and affect quality of life. Psychological interventions like brief psychoanalytic psychotherapy and mindfulness-based therapies, including Acceptance and Commitment Therapy (ACT), were discussed as therapies shown to improve outcomes, reducing symptoms of anxiety and depression while enhancing overall well-being. The importance of mental health support is undeniable; however, the Living with Lupus in 2020 survey found that only 26.2% of patients across Europe have access to professional psychological support, emphasising the need to improve access to mental health services for lupus patients.

Dr. Moroni's presentation concluded with a call for a more holistic approach to lupus care, integrating mental health treatments such as psychotherapy, mindfulness, physical exercise, and addressing sleep and sexual health issues. This comprehensive care model aims to support patients in managing both the physical and potential emotional burdens of lupus, ultimately enhancing people's quality of life.



Lupus and
Mental Health

... from a young doctor's perspective

# Meet the Doctor

## with Doctors Chris Wincup & Luca Moroni

The "Meet the Doctor" session offered a unique opportunity for delegates to engage in an open Q&A with two physicians in attendance, Dr. Chris Wincup and Dr. Luca Moroni. This engaging and fascinating session allowed delegates to ask open questions and engage in direct conversations with the doctors about anything to do with lupus in a safe space.

While we are unable to share specific questions raised due to confidentiality, the themes discussed included important and often underdiscussed topics such as mental health, tattoos, the use of drugs and sex and sexuality. The session provided valuable insights and fostered a very open dialogue between the doctors and national delegates.

# How can we increase the dialogue and co-working between Lupus Europe and its members?

This was a key session, a listening exercise focused on identifying the needs of National Members and on identifying strategies to increase the collaboration and communication between Lupus Europe and its national member groups. The discussion brought forward a range of ideas for strengthening partnerships, overcoming challenges, and creating more effective channels of communication.

Delegates were split into smaller groups to encourage participation and foster focused discussions on key questions. Each group rotated around different flipcharts that were set up with specific questions and themes. A Board or Extended Board Member stood next to each flipchart to facilitate the discussion. This process allowed each group to contribute ideas and responses to multiple aspects during the session.

Each flipchart contained a question or theme that was central to the topic of increasing dialogue between Lupus Europe and national groups. Flipcharts had many questions such as “would connecting with other national groups be of interest?”, “What are the main problems/barriers you are facing?”, “Is there something missing from Lupus Europe projects that you would like us to do?”, “How do you want us to engage? Means of communication (i.e. phone, Zoom, written materials, e-mails, in person)”, “How are you engaging with Lupus Europe today and what are your priorities? Do you have the capacity you need in relation to Lupus Europe?”, “How Can Lupus Europe Help National Groups?”.

Small groups of delegates would gather around a flipchart, discuss the theme, and write down their ideas on the flipchart. These responses were recorded in real time, allowing everyone to see the ideas and thoughts shared by other groups. After spending some time at one flipchart, the groups rotated to the next one to contribute to the next question or theme. This process helped ensure all delegates engaged with all topics and contributed to the discussions, allowing for a broad range of ideas and insights to be shared and enriching the session’s outcome. This method created a dynamic and engaging environment for delegates to reflect, collaborate and give ideas on all topics, encouraging creative thinking and group problem-solving!

At the end of the small group work, key points from each flipchart were presented to the larger group. This allowed for a quick summary of ideas and the fast identification of priority actions.

An important discussion point was the importance of proactively thinking about how to further improve communication between national groups and Lupus Europe. Participants proposed the creation of a centralised online platform or webpage where relevant information about events, activities, and ongoing initiatives could be shared. This would enable each national group to stay updated on activities happening in other countries and provide a space to promote shared projects, discussions, and progress.

QR codes were suggested as an effective tool to easily access this shared information, potentially placed on printed materials or project cards, making it easier for delegates and members of national groups to engage with the content on the go.

To further enhance communication, regular meetings were recommended to create frequent touchpoints to share updates, discuss upcoming initiatives, and ensure alignment across member groups.

A significant focus was also placed on the importance of partnership-building between national groups and other organisations, both within and outside the lupus community. Delegates emphasised that by collaborating with key external partners, groups could strengthen their resources, exchange knowledge, and amplify the impact of their advocacy and support programs.

Delegates also discussed how this could also be a chance to create opportunities for capacity-building programmes that foster knowledge transfer, particularly for younger members and volunteers. Programmes that connect groups in various countries could help disseminate best practices, lessons learned, and practical tools for managing lupus advocacy, awareness, and patient support.

Delegates highlighted the potential of digital media to increase the outreach and engagement of the lupus community. One suggestion was to create a podcast series where national group representatives could share their stories, experiences, and expertise on various lupus-related topics. These podcasts would serve as an outreach tool, connecting delegates across countries, amplifying national voices, and providing a platform for storytelling that could resonate on a larger scale.

One of the main barriers discussed during the session was the challenge of language differences across groups and countries. National groups may face difficulties in understanding key resources available in English, which can prevent members from fully engaging with LE's initiatives. The conversation focused on the need to prioritise consistent use of translation tools across Lupus Europe materials, ensuring that language is no longer a barrier to participation. Additionally, the idea of increasing the use of translation tools across online platforms was mentioned. By integrating translation tools on Lupus Europe’s website and other communication platforms, groups may be able to engage more effectively, irrespective of language barriers.

Additionally, lack of awareness about available resources within national groups was mentioned as a challenge. Many delegates expressed that Lupus Europe’s tools and resources were not always fully promoted by the national groups. As a solution, participants suggested greater emphasis on increasing visibility of these resources through targeted outreach and awareness campaigns.

In-person contact was also considered essential for establishing strong, trusting relationships between national groups. Several delegates proposed increasing face-to-face meetings and leveraging Zoom calls for certain types of engagements, aiming to bring a more personal touch to interactions and encourage deeper collaboration.
Delegates highlighted the importance of sharing country news through regular updates across National Groups, to keep everyone informed about ongoing projects and initiatives. Providing practical information about what members can gain from working with Lupus Europe, particularly regarding open projects and opportunities for engagement was also emphasised.
There was a request for practical training on how to use tools like the HTA toolkit, aimed at strengthening the capabilities of National leaders and national groups. Generating best practice guidelines for Zoom meetings, particularly for smaller groups, were suggested to enhance communication between National leaders and delegates outside of larger gatherings.
Emails and social media campaigns (such as Facebook) were highlighted as effective ways to reach delegates. There was strong support for Zoom meetings, particularly for staying connected with specific groups or work and for 1:2:1 meetings between Lupus Europe representatives and local leaders. These types of meetings help maintain ongoing dialogue. Delegates also emphasized the importance of face to face meetings when possible, with the understanding that these would be scheduled for crucial discussions or major events.

Delegates expressed a need for more information on ongoing projects from LE, so national groups could stay informed about activities and initiatives. Training for national groups on how to communicate effectively with Lupus Europe and present their activities to local organisations was discussed. This includes guidance on how to present Lupus Europe’s work and mission at the national level, ensuring better alignment and visibility. There was a request for training on patient engagement, particularly focusing on how to communicate with doctors effectively and on how to attract volunteers.

Delegates expressed a wish for personal meetings with Lupus Europe Board members to foster stronger connections with National Group members and receive guidance. Delegates also discussed the need for training national organisation volunteers, specifically focusing on recruitment and retention of volunteers to sustain and expand national groups going forward.

Training on how to attract and retain volunteers, particularly by highlighting the benefits of volunteering and the role volunteers play in supporting the goals of national organisations was discussed.  Another discussion point was training for national group members on how to manage and promote national groups effectively, ensuring better volunteer engagement and enhancing organisational skills. Other training suggestions included data-sharing workshops.

Delegates also the need for more active outreach, particularly through webinars and in-person presentations at National Group meetings. Several delegates expressed a desire for Lupus Europe to take a more proactive role in outreach, especially to National Groups that may not be as familiar with Lupus Europe’s work or who may not have the resources to engage regularly.

Focusing on understanding how National Groups are currently engaging with Lupus Europe and what their priorities are moving forward was insightful as well.

Several delegates mentioned they are actively participating in initiatives such as the Patient Advisory Network (PAN) or had participated in testing LupusGPT or volunteered for the Lupus100 project, though some people noted challenges such as insufficient time or limited resources for effective participation in projects. There was a clear recognition that financial resources and reliable volunteers, particularly younger people, are critical to sustaining the engagement from National Groups with Lupus Europe.

Delegates also noted that while there is active participation in social media campaigns and email communications, they expressed a desire to streamline engagement efforts, suggesting the creation of a single group for Lupus Europe on social media to avoid redundancy.

There were also discussions about the need to reengage with some National Groups emphasising that sharing Lupus Europe projects and collaborating on initiatives is crucial for improving the synergy between National and European efforts. In addition, it was suggested that volunteers from National Groups could be leveraged to support Lupus Europe initiatives more effectively, especially in areas such as capacity building or resource development.

As far as priorities go, there was a strong emphasis on building capacity in National Groups, particularly by improving training and providing the right tools for volunteers.

All in all this session was an important step toward building an even stronger, even more connected European lupus community.

# Mental Health First Aid Training

by HealthFirst

Empathetic conversations

*Strengthening peer support for lupus*

Dr Michelle Wright
Dr Mecky McNeil

## Empathetic Conversations: Strengthening Peer Support for Lupus

In a session led by Dr. Michelle Wright and Dr. Mecky McNeil, delegates were introduced to the concept of empathetic peer support for people living with lupus. National delegates are often the first point of contact for people post-diagnosis and national lupus groups frequently provide peer support to people with lupus.

The session aimed to equip delegates with the necessary tools and frameworks to offer effective, compassionate support to other people navigating lupus. The session was designed so that delegates could take back all tools and skills learned to their national groups and disseminate the knowledge.

The presentation began with an exploration of the role of a peer supporter, emphasising that this role is not that of a therapist or medical advisor. Peer supporters are tasked with offering emotional and practical support, while respecting boundaries and maintaining confidentiality. The session also highlighted the importance of self-care for peer supporters, introducing the concept of the "stress container" to illustrate how stress can accumulate and the need for proactive coping strategies to manage it effectively.

Dr. Wright and Dr. McNeil highlighted key self-care practices that peer supporters can incorporate into their routine to maintain their own well-being while supporting others. Such practices include physical care (i.e. resting or moving one's body) and emotional care (i.e. connecting with others or unplugging to recharge). The ACT Now! framework was introduced as a structured approach to offering support to people with lupus. This framework includes the steps: Approach, Communicate, and Take Action and it encourages peer supporters to assess their readiness, communicate effectively, and take appropriate action to support a person.

An in-depth example of a case study of Sarah was prepared for this session, with the help of people with lupus. Sarah, in this case study example, was a 32-year-old marketing executive recently diagnosed with lupus. Delegates split into small group work, as this case study was used to illustrate the challenges faced by people with lupus and how peer supporters can best offer support. The group work session allowed delegates to discuss the emotional states peer supporters might encounter, such as feelings of overwhelm, self-doubt, and confusion, and how to manage these reactions effectively while supporting another.

The session wrapped up with a focus on personal housekeeping for peer supporters, highlighting the need for post-conversation reflection, emotional check-ins, and setting boundaries. A variety of self-care tools, such as the 5-4-3-2-1 grounding exercise and square breathing techniques, were provided as immediate strategies for managing overwhelm during peer support interactions.

Dr. Wright and Dr. McNeil's session emphasised the critical role of peer support in helping people with lupus manage the possible psychological and emotional challenges of their diagnosis. By offering empathetic, well-informed support, peer supporters can make a meaningful difference in the lives of people living with lupus. This training was particularly valuable for national delegates, providing them with the skills and knowledge needed to even more effectively support people with lupus in their countries.

# Getting the **Inside Perspective**

## Diversity Session – Getting the Inside Perspective

This was a highly interactive, listening-focused session that encouraged delegates to think collaboratively about a key issue for the European lupus community. Together, we reflected on the efforts of National Groups across Europe to engage with diverse, often underrepresented voices and on tangible ideas for next steps. In alignment with Lupus Europe's 2025 theme of "Every Voice Matters", the session sought to explore what strategies have been successful in reaching diverse groups, where further efforts are needed and how we can move forward.

Delegates were invited to work collaboratively around flipcharts with post its, sharing their experiences. Each flipchart featured questions that sparked discussions around what had been tried in their National Group, what worked, and what didn't. They were then asked to brainstorm ideas to improve diversity and inclusion within the European lupus community.

Successful initiatives delegates shared with us included meetings with non-members; some groups had tried to reach out to those outside their immediate circles, which was seen as a positive effort for broadening engagement. An intriguing idea was information sessions in clinics; these were found to be successful in raising awareness and reaching diverse groups of patients. Delegates also discussed the positive impact of engaging in targeted charity efforts in their countries to raise awareness and funds for lupus while promoting inclusivity. Featuring diverse voices in lupus-related publications, like the NVLE magazine, was highlighted as an important step forward. Recognising and celebrating volunteers' various cultural backgrounds to help foster a more inclusive environment was brought up as well.

In terms of barriers, language difficulties came up repeatedly as a major obstacle to effective communication and inclusion of diverse voices. Lack of consistent engagement was a difficulty with some initiatives failing to reach their target audience due to inconsistent or insufficient outreach. In certain cases, the initiatives trialled did not resonate with the intended groups, highlighting the need for more tailored approaches.

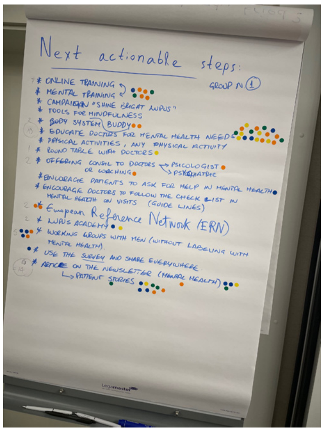
The question "what should we start working on together" invited delegates to share ideas on tangible actions we can take to move forward on this topic. Several ideas emerged, reflecting a broad commitment to increasing inclusion and enhancing our collective reach.

Delegates mentioned the potential to expand outreach to specific communities to strengthen engagement, i.e. working with rural populations and South Asian communities. Involving men more effectively was highlighted as a key point, as some National Groups found that men were less likely to engage in lupus-related activities or support groups. Reaching elderly people by creating spaces for social clubs and engagements tailored to their needs was also mentioned. Celebrating diverse cultural heritage was suggested in this category as well, as one of the possible ways to make everyone feel seen and valued.

Delegates stressed the need to improve access to resources, particularly for rural populations or those with disabilities. Developing more accessible, culturally relevant materials, such as pamphlets or educational content in different languages, also emerged as a priority. Using social media to share lupus stories, particularly from underrepresented voices, and to ensure these stories are not left out of the public discourse. The idea of collaborating with external organisations, where relevant, arose in many discussions. Providing training to volunteers on how to engage and support people from different ethnic backgrounds and how to engage with and support diverse lupus communities effectively was also proposed.

This session provided an invaluable opportunity to explore the current landscape of diversity within the European lupus community and identify possible tangible ways forward. Through collective brainstorming and sharing of ideas, actionable steps that Lupus Europe and its National Groups can take to better represent and engage all voices in the European lupus community were highlighted.

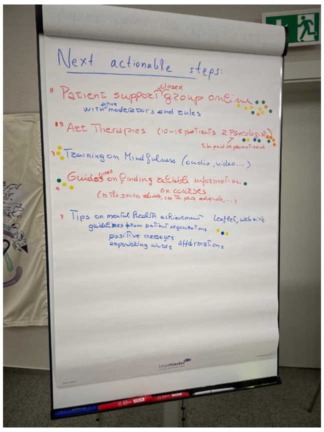
# Mental Health Workshop B



Next actionable steps:

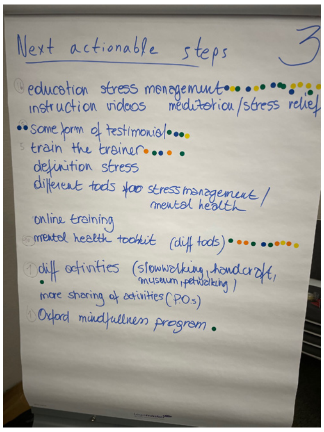
GROUP N. ①

7 * ONLINE TRAINING
* MENTAL TRAINING
* CAMPAIGN "SHINE BRIGHT LUPUS"
* TOOLS FOR MINDFULNESS
2 * BODY SYSTEM BUDDY
⑲ * EDUCATE DOCTORS FOR MENTAL HEALTH NEEDS
* PHYSICAL ACTIVITIES, ANY PHYSICAL ACTIVITY
1 * ROUND TABLE WITH DOCTORS
2 * OFFERING CONSIL TO DOCTORS → PSICOLOGIST → PSYCHIATRIC OR COACHING
* ENCORAGE PATIENTS TO ASK FOR HELP IN MENTAL HEALTH
* ENCOURAGE DOCTORS TO FOLLOW THE CHECK LIST IN MENTAL HEALTH ON VISITS (GUIDE LINES)
2 * European Reference Network (ERN)
2 * LUPUS ACADEMY
5 * WORKING GROUPS WITH MEN (WITHOUT LABELING WITH MENTAL HEALTH)
* USE THE SURVEY AND SHARE EVERYWHERE
⑭ * ARTICLE ON THE NEWSLETTER (MENTAL HEALTH)
↳ PATIENT STORIES



Next actionable steps:

11 Patient support closed group online
with active moderators and rules
9 Art Therapies (10-15 patients 2 psycologist)
to be paid or promotional
3 Training on Mindfulness (audio, video....)
4 Guidelines on finding reliable information on courses
(is the source reliable, are the price adequate, ...)
3 Tips on mental health achievement leaflet, website
guidelines from patient organizations
positive messages
empowering words affirmations



Next actionable steps 3

⑯ education stress management
instruction videos meditation/stress relief
⑤ some form of testimonial
5 train the trainer
definition stress
different tools for stress management / mental health
online training
⑩ mental health toolkit (diff tools)
① diff activities (slowwalking, handcraft, museum, petwalking)
more sharing of activities (P.O.s)
① Oxford mindfullness program

This was an action-oriented session focused on identifying tangible actions to begin addressing some of the challenges identified in the previous session, Mental Health Workshop A.

Delegates used flipcharts to capture ideas and solutions. This interactive approach allowed for a dynamic exchange of ideas and ensured that all delegates had the opportunity to contribute to shaping actionable steps. Delegates were then asked to vote for their top actions and the top three actions were identified. A separate feedback session allowed the entire group to hear and discuss the input and ideas of all delegates in terms of possible, concrete actions.

Throughout this session, delegates were highly engaged and worked collaboratively to propose actionable solutions.

Several suggestions were discussed, some of which can be found below. A number of delegates focused on providing education and resources around stress management, such as creating instructional videos, promoting meditation and stress relief activities, and training community members to become trainers in this area. Online training was highlighted as an effective method for spreading stress management and mental health techniques, including mindfulness and relaxation practices.

It was noted that peer support groups could be of great use online, but they should have rules and moderators to ensure structured discussions. Providing a platform where patients could connect with each other was seen a key.

Delegates suggested offering mental health training to doctors, to support them to recognise and address mental health issues more effectively in lupus patients. Additionally, providing training programs to patients was also proposed to help create support networks. Participants also raised the idea of creating mental health toolkits, which would be a collection of resources and guidelines for lupus patients to access psychological support. The toolkits could focus on stress management, self-care, and understanding the connection between mental health and lupus. Another idea that was discussed was the use of art therapy, which could be offered in smaller, in person group settings (10-15 people). The idea was to combine creative expression with mental health support.

Delegates then voted on the most actionable suggestions using dots to prioritise their choices.

**The top three most voted suggestions were:**

Online doctor education: This was highly favoured, with many delegates voting for the implementation of accessible, online mental health training for doctors.

Sharing Data highlighting that mental health is a potential issue in lupus: This was another top choice, with many delegates selecting this as a key action point

Education on stress management: This received many votes as a top priority for patients.

At the end of this session a concrete action was immediately introduced with the launch of a mental health training option for delegates through Lupus Europe. Delegates could attend the six-week training at no cost and could then take back learnings to their National Groups, ensuring wide dissemination of information and insights across the European lupus community. Almost all delegates in attendance volunteered to join this course. This highlights the significant need for and importance of such trainings in the lupus community.

# Patient Testimony

## with Petra Balážová

During the Lupus Europe Convention in Bratislava, Petra Balážová from Klub Motylik led a powerful "Patient Testimony" session. Unlike traditional presentations, this session was structured as an open discussion where delegates sat in a circle and shared their personal experiences without any kind of script. The group freely discussed topics that were of interest to them, including the critical role of physical exercise and nutrition in managing lupus.

Delegates openly shared how physical activity, and a balanced diet have impacted their lives. Many described how adapting physical exercise—whether through yoga, swimming, or walking—helped them regain strength, reduce stiffness, and manage fatigue. Some people acknowledged the difficulties of maintaining motivation during flare-ups, yet the common thread throughout was the empowerment derived from listening to their bodies and finding a personalised approach to movement.

The discussion highlighted that while lupus presents unique challenges, small, consistent lifestyle adjustments—such as personalised exercise routines and mindful eating—can significantly enhance overall well-being and quality of life. Petra’s session was a powerful reminder of the strength found in shared experiences and the importance of finding what works for each person.

# Nordic Walking

## with Lucia Okoličányová

The Nordic walking session, led by Lucia Okoličányová, President of the Slovakian Nordic Walking Association, was a great experience for delegates. Over the course of 1.5 hours, participants had the opportunity to try this dynamic form of exercise, known for its ability to engage the entire body while being low-impact and easy on the joints.

Lucia introduced Nordic walking, often described as walking with poles, to participants, many of whom were complete beginners to the activity. Despite having no prior experience, the group quickly learned the technique under the guidance of our excellent instructor who broke down the movements and ensured everyone felt comfortable. The session began with a brief demonstration of the correct posture, stride, and pole technique to maximize efficiency and reduce any risk of injury.

The walk took participants across the Danube Bridge, offering stunning views of the city at dusk, while also serving as a scenic and peaceful route to practice the technique. The group enjoyed the beauty of the environment, along with the camaraderie of trying something new together! Nordic walking provided a great introduction to a physical activity that emphasises cardiovascular health, improves posture, and tones muscles. The addition of poles helps distribute the effort across the upper body, making it a great option for exercise for people looking for exercise that is low impact for joints.

As the session progressed, participants found themselves not only having fun but also feeling surprisingly engaged by the activity's combination of physical movement and focus. The simplicity of the technique made it accessible, yet it still provided a full-body workout that left participants feeling energized!

SOFT SKILL TRAINING

# How to Grow

by Alain Cornet

Alain Cornet led a very interesting session on "How to Grow", offering a compelling and interactive discussion on personal and organisational growth. The session focused not only on fostering growth in the lupus community but also on how people can cultivate their own leadership skills and growth as part of their national groups.

This session aimed to help delegates develop actionable insights on growing both people and organisations by applying the GROW model—a framework designed for structured conversations focused on goal setting, problem-solving, and personal development. The goal was for each participant to leave with a personal first step or a practical tip that would allow them to grow themselves and other people in their national groups.

Alain introduced the GROW model, which stands for Goal, Reality, Options, and Willingness. This model encourages a structured approach to helping people achieve their goals, highlighting the belief that the best person to find a solution to a problem is the person experiencing it. One of the keys to effective growth discussions is active listening, which allows individuals to explore and clarify their goals before seeking resolutions.

The session began with an exploration of the situation: delegates were asked to identify one specific opportunity for either themselves or someone in their group to grow. Each participant was tasked with reflecting on a personal or organisational goal, writing it down, and considering how they might approach achieving it.

The delegates were divided into pairs for an interactive exercise where they got the chance to practice the active listening skills needed to help someone develop their goal. One person in each pair was the “focus,” working on their identified goal, while the other person, acted as a “support” and used active listening to help them explore their situation and clarify their goal. The support person would guide the focus person to refine their goal using the SMART framework—ensuring it was Specific, Measurable, Achievable, Relevant, and Time-bound. Delegates gave a short, 3–4-minute presentation to the entire group, discussing their identified goal and how they might approach achieving it.

The group discussed the difficulties and challenges they encounter when trying to help others grow. One group considered why they are not always growing others as much as they ideally would like, while others explored what people can do that helps others grow and the importance of setting the right goals for personal and organisational development.

The next part of the session encouraged delegates to lean into creativity to think about potential solutions to challenges. Participants were invited to share their “fantasyland solutions,” exploring out-of-the-box ideas and then narrowing them down to practical and implementable steps. This creative brainstorming allowed delegates to develop new perspectives on problem-solving and growth strategies.
At the end of the session, delegates were tasked with writing down the concrete steps they would take to pursue their goals. They were encouraged to outline their next steps using the SMART framework and to anticipate obstacles that might arise along the way. Each participant was asked to write their action plan on a piece of paper and place it in an envelope with their name, date, and goals. This envelope was then posted to them after the Convention. This exercise emphasised personal commitment to growth and provided a tangible way to track progress after the convention.

A central theme of the session was the value of a growth mindset, the belief that it is possible for people and organisations to evolve through dedication and effort. Delegates left with practical tools to apply in their own communities, such as how to set goals effectively, the importance of active listening, and tangible strategies for fostering both personal and organisational growth.

The session also emphasised that mentorship, collaboration, and strategic planning are key to navigating the challenges and opportunities within the lupus community. Alain’s approach helped delegates not only reflect on how to grow their organisations but also encouraged them to think about their own personal growth as leaders within the lupus community.

# Closing

Jeanette Andersen, Lupus Europe Chair, closed the Convention with a reflective, forward-looking and fun wrap up session. Jeanette recapped the key themes and discussions from the Convention, highlighting the valuable insights shared in sessions.

Key takeaways included the importance of mindfulness, physical activity, sleep, and sex in managing anxiety and depression! The session emphasised the need for greater focus on mental health in both patient care and within lupus communities, as well as the development of training for doctors on mental health.

Looking ahead, Jeanette outlined concrete next steps, including the creation of new working groups on mental health and diversity, the importance of increased communication between national groups and Lupus Europe, and the need for national groups to share information about their projects with Lupus Europe. The session also touched on the potential for future webinars and Zoom meetings to further strengthen communication between Lupus Europe and its National Members.

In closing, Jeanette expressed her gratitude to all the delegates, reinforcing the importance of the community's collective work. The session left attendees with a clear vision for the next steps and an increased drive to continue working together for a fulfilling life for all people with lupus in Europe!