

LUPUS EUROPE

CONVENTION 2023

Lisbon, Portugal | 28th April to 1st May 2023

report



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Introduction

The theme for Lupus Europe Annual Convention 2023 was “**Volunteering**”. Lupus organisations in Europe are patient-led and volunteer based; volunteers are the life force of our organisations. Being a volunteer can be incredibly rewarding, can enhance skills and create a sense of being part of a family of like-minded individuals working together for a common purpose.

40 delegates from **18 countries** and **8 industry partners** joined the Convention. **13 members of the Lupus Europe PAN** (Patient Advisory Network) from 11 countries also joined the Convention.

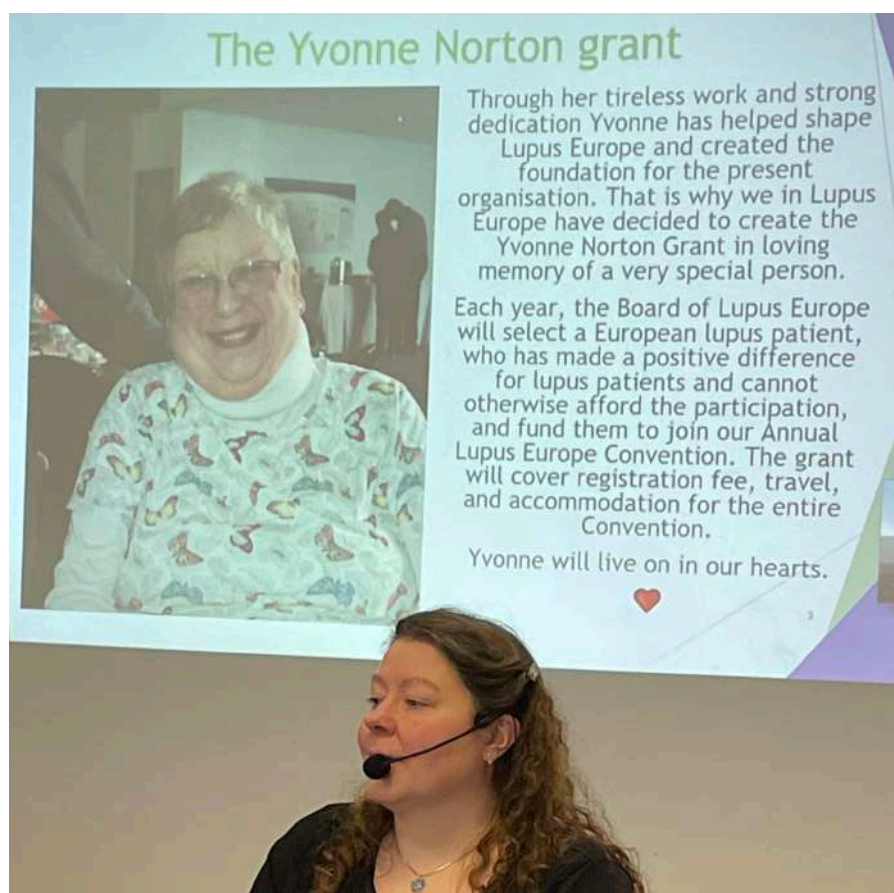
Please note that the summary below is based on notes taken by the secretariat and reviewed by some Board members. It should not be taken as a complete and literal abstract of the presenters' work and might contain simplifications or unintended omissions. Slides used by the presenters are available for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

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 Patient Advisory Network (PAN), this was already the 2nd day of meeting as they met on the Friday for a full day, both to benefit from a key workshop on "Patient Doctor Communication", to share their progress in the many projects they are involved in, and to discuss issues of common interest.

During the opening session of the Lupus Europe Convention 2023, Jeanette introduced the **Yvonne Norton Grant**, honouring the legacy of Yvonne Norton and her immense contributions to the lupus community. This annual grant aims to support European lupus patients who have positively impacted the lupus community and lack the means to attend the Lupus Europe Convention, providing them with full coverage for registration, travel, and accommodation.

Jeanette shared the full agenda of the Convention, where workshops on the volunteering toolkit were important components, and also introduced the current year Convention theme: "Volunteering". This last year, leaders of national lupus groups across Europe and Lupus Europe have come together in a vibrant and energetic volunteering working group to discuss how volunteering works for different European organisations, to find common ground on best practices across organisations and to look for creative solutions on a topic that concerns us all! As organisations, we are always stronger when we stand together.



PAN Meeting & Workshop

PAN Meeting

On Friday May 26th, our **Patient Advisory Network (PAN)** members had a Pre-Convention Day **General Meeting** followed by a PAN training session including a **workshop on the theme “Timelines”**.

The day started with the PAN General Meeting with **practical information on updates and available opportunities** for the PAN members to learn more about. The general meeting was followed by a **training session presented by Jeanette Andersen**, chair of Lupus Europe, where the PAN members got to practise their presentation preparations by **building their own timelines**. Both meetings were hybrid so PAN members who were unable to join us in person could take part.



Patient Doctor Communication Workshop

For a long time, Lupus Europe has had an interest in examining the patient-doctor communication and searching for possible solutions to improve it. Right before the 2023 Convention, we were contacted by the ERN ReCONNET about the possibility of co-authoring an article on the subject, seen from both doctor AND patient perspective. As we had a time slot free for PAN members working with the EMA and early arriving Convention delegates on the Pre-Convention Day, we made the decision to have a workshop on the topic and gather the patient perspective through a small focus group discussion.

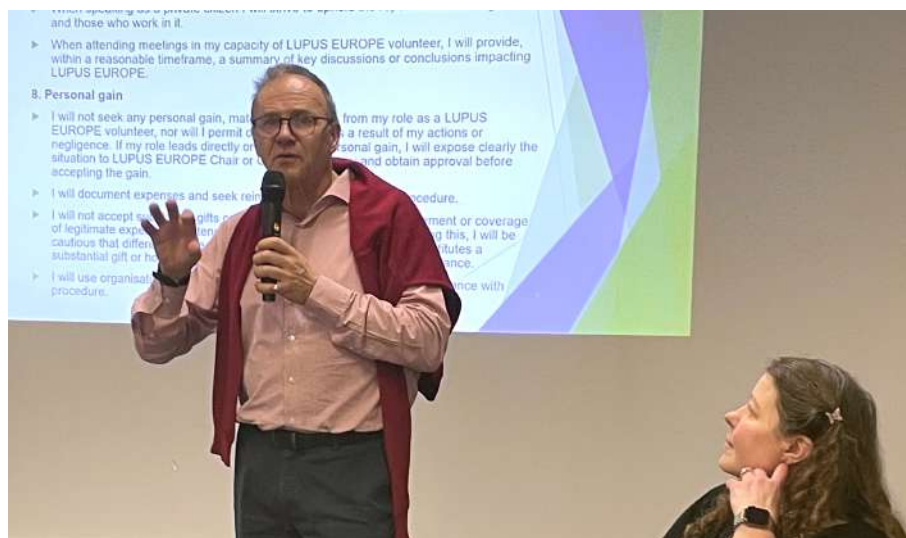
The discussion touched upon different areas that can make the communication challenging like:

- **time constraints:** if you only have 20 minutes for a consultation and you also need to go through all the latest test results and an examination, that doesn't leave much time for discussing how the patient feels and functions.
- **changing doctors:** if you have to change doctors often, chances are you won't be able to connect properly and establish a level of trust and understanding, where you feel comfortable discussing personal issues and furthermore the patient is responsible for remembering and conveying what other doctors have done previously.
- **cultural gaps:** as in any human relation, skills and styles impact the communication and the tone of the patient-doctor collaboration.
- **language:** if you do not speak the same national language and need an interpreter, the communication will never have the same quality and some things will inevitably get lost or be misunderstood. There might also be a language barrier in the level of communication: for example If the doctor uses difficult medical terms and the patient does not understand them

As we all know, lupus as a very heterogeneous disease and no two patients experience their disease the same way. That opens up a discussion on "what constitutes a flare?" Patients will often focus on differences in the way they feel and *their* experience of their disease, whereas the doctor focuses on biomedical tests and values. As a patient expressed, "*What is not measurable or treatable does not exist and is not discussed in the consultation*". The patients' experience is that health related quality of life (HRQoL) things like fatigue or pain are not taken "seriously" by the doctor, because it cannot be objectively measured, and they do not have a treatment for it. At the same time those areas are seen as the most bothersome symptoms from the patient's perspective.

Possible solutions for the communication gap were also discussed. There are many things that can be done from the patient's side to help improve the communication. Patients can help by preparing for their consultation: preparing a list of questions and concerns beforehand, identifying priorities and asking a trusted person to join in appointments for support. During the consultation the tips include asking the doctor to explain medical terms and treatment options in a plain language, asking for visual aids and clarifying their own role in the decision-making process. The patient's own skills in managing the disease will also impact the patient-doctor communication. Therefore, it is advised to become an "expert" on your own body and *your* lupus. Which things help you manage your disease better? What can trigger a flare for you? Which medication are you taking and for what reason? etc. Another thing that might help improve the communication is adding a lupus nurse to the team. A nurse can provide substantial support, often in a more informal way before and after the consultation, helping the patient to sort through important or less important questions, confirming understanding of what was discussed in the consultation, or touching on some of the more sensitive topics in a softer context.

The results of the focus group discussion have now been added to the doctor's perspective in an article called "The communication GAP between patients and clinicians and the importance of patient reported outcomes in SLE ", which was co-created by doctors and patients and will hopefully be published very soon.



Games & Dinner

Our Friday evening started with the arrival of delegates from Lupus Europe member organisations and industry representatives. After a warm welcome from the Board, all present joined the ice breaking games.

With microphone and balloons in hand, Alain and Dalila led the participants into the first game where we got to know a little bit more about the participants and their backgrounds. A little bit of running while thinking fast was the perfect pre-dinner workout for everyone! The next two games allowed the participants to personally introduce themselves after asking interesting questions to each other.

And, after such a great time, everyone was pleased to know that it was time to join our special opening dinner and to have some delicious typical local dishes.

The opening convention dinner was a lovely opportunity to meet old friends and to make new ones. There were many new attendees to our convention this year which was so great to see.



Volunteering

by Elsa Mateus



Elsa Mateus, the president of the Board of the Portuguese League Against Rheumatic Diseases (LPCDR) and a prominent figure in various patient organisations, has a rich history of volunteering. Elsa talked about how in her teenage years, she became volunteer at a local radio station, gaining valuable experience and training in journalism. Throughout her college years, she joined a folklore group and coordinated exhibitions and events related to traditional culture, all on a voluntary basis.

After 2000, Elsa Mateus shifted her focus to patient organisations and advocacy work. She became a volunteer for Portuguese organisations and represented the Portuguese League Against Rheumatic Diseases at international events. Elsa Mateus recognized the need for change within her patient organisation, as the concept of volunteering at the time was limited to organising activities like races and picnics. She proposed improvements such as a volunteer handbook, streamlined recruitment processes, and introduced certificates to acknowledge volunteers' contributions and skills.

Volunteering has been an enriching experience for Elsa Mateus, providing personal growth, skills development, and a sense of purpose. For Elsa, volunteering not only helps others but also fosters confidence and self-esteem. She made efforts to expand the scope of volunteer work, emphasising community-building and sustainability. She introduced digital tools like QR codes to reduce paper usage and repurposed old newsletters to create bags, promoting environmental awareness.

To recruit more volunteers, Elsa identified six project areas tailored to different interests and abilities: peer support, awareness activities, specialised technical services, logistic support, leisure activities, and creative and occupational activities. However, she also acknowledged several hurdles and challenges. Legal requirements, including training, social security coverage, and occupational safety measures, can be demanding for organisations. Finding volunteers who can commit time, especially on weekdays, while facing external constraints like work or childcare, can be challenging.

To overcome these obstacles, Elsa Mateus adopted various strategies. She engaged young volunteers, such as social communication students and rheumatologists, to assist with social media, content revision, and translation. Collaborating with universities and the city council provided a pool of volunteers for specific needs. These measures helped address the fluctuating availability of volunteers.

Elsa's volunteering journey has been rewarding and educational. She has embraced evolving concepts surrounding volunteering, continually adapting her approach to meet changing needs.

LUPUS EUROPE Strategic Plan

We have started this year with a new and exciting Strategic Plan in place for the next years to come, and those who attended our Lupus Europe Convention had the opportunity to learn more about it in a new different and very dynamic way: a Strategy Quiz. Our Convention attendees were divided into mixed groups of old and new PAN members, industry representatives, and Board members. The groups chose their own very creative names such as “Papillion”, among others!

With no time to spare, all the groups were given a challenging quiz around Lupus Europe strategies and had the chance to ask for (only!) a few hints. Great discussions arose around Lupus Europe Strategies, and all participants worked hard on getting the right answers. There was lots of fun and very nice pictures taken during the activity. The big moment arrived at the time of revealing the right answers! Who was going to win? They all did a wonderful job and were given a printed copy of the book Lupus100 to take home. Congratulations to everyone who participated. We are sure that everyone learnt more about Lupus Europe and Lupus Europe’s Strategic Plan for 2023-2028!

Poster Tour

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





INTERNATIONAL VOLUNTEER DAY: 5TH DECEMBER 2022

Activity title «I Beautify my garden»

Nicolaou A. Mousouri K.Ch.

//BACKGROUND

The 5th of December was established as International Volunteer Day in 1985, by a decision of the UN General Assembly to pay tribute to the millions of volunteers who are committed to this institution.

The week of 1st to 8th of December was designated by the Pan Cyprian Volunteerism Coordinative council (PCCV) as a volunteering week, where all associations were invited to organize an action, under the umbrella of volunteering. So on Sunday 4th of December, CYPLER organized the action "I beautify my garden". Where members of the LUPUS group of Cyprus participated as volunteers.



//OBJECTIVES

- To raise awareness for volunteering
- Pruning, cleaning and transplanting in the garden of the office of Larnaca
- The social circle of our members to be expanded, but also to strengthen their existing relationships through volunteering
- More will be informed about CYPLER from the Pan Cyprian Volunteerism Coordinative council through their magazine and through their social
- To send the message that volunteering is important as you provide essential help for worthy cause

//METHOD

- Informed from the Pan Cyprian Volunteerism Coordinative council, set the date and inform the board for final approval, 6 months in advance.
- The application form was completed and sent to Pan Cyprian Volunteerism Coordinative council
- Our next step was to prepare the action plan
- The Poster and the social media announcements were prepared
- Members were informed through sms, mail, FB and by telephone communication.
- Research and purchase of plants and whatever else we needed for the action
- A plan for the day was prepared based on the number of registrations we had



//RESULTS

30 people participated

Our garden was beautified

3000 Facebook page visits through the two weeks that we posted the action

We had 310 like

//CONCLUSIONS

Undoubtedly the event was in huge success. The volunteers spent a pleasant and creative day, having the opportunity, in the end, to get to know each other enjoying a hot drink.




//NEXT STEPS

In view of the World Volunteer Day in 2023, CYPLER will once again organize an action aimed at highlighting the importance and benefits of volunteering with the ultimate goal of growing the CYPLER volunteer team.

Our aim is to give our volunteers the opportunity to find the place that suits them in the organization, because volunteering should be something that will offer them joy and pleasure and not another obligation of the day.



Gruppo LES Italiano shared with us a very interesting poster about their project “SLExpert for you”; a telephone counselling service aimed at answering patients’ questions about lupus.



The poster is for 'LESperto per te', a telephone counselling service. It features the logo of Gruppo LES Italiano ODV and a woman's face. The main title is '« SLExpert for you » direct line with a Rheumatologist'. The text describes the service as a toll-free help line for lupus-related questions, staffed by specialists and volunteers. It includes the phone number 800.227978 and the operating hours: Monday and Friday from 15.30 to 17.30, and Tuesday to Thursday from 10.00 to 12.00. A section titled 'L'impatto del LES' states that 76% of people declare fatigue caused by lupus, leading to reduced social activities. The bottom of the poster mentions the project's success and the contribution of Astra Zeneca.

Gruppo LES Italiano ODV

LESperto per te

LESperto per te
Un filo diretto con uno specialista Reumatologo
Scopri di più

« SLExpert for you » direct line with a Rheumatologist

«SLExpert for you» is a telephone counselling service aiming at answering the many doubts and questions that people with lupus ask every day by calling our toll-free help line.

Our help line so far has only been conducted by our volunteers.

Doubts and questions to which only a Specialist can answer !!!

For that reason, in October 2022, in connection with the **Lupus Awareness Month**, we launched the project “SLExpert for you”. The project includes the participation of five Rheumatologists who in turn answer the patients and caregivers who call our help line for support:

Every Monday from 15.30 to 17.30
Every Friday from 13.30 to 15.30

Numero Verde
800.227978

Thanks to our volunteers, our help line is also active from Monday to Thursday, from 10.00 to 12.00 and from 15.30 to 17.30.

Sostenere **Motivare**
Supportare

Alcune manifestazioni non visibili
nefrite lupica
dolori articolari
psicosi
miocarditi

L'impatto del LES
Il **76%** dichiara che la **stanchezza** causata dal Lupus li ha costretti a ridurre le **attività sociali**

LESperto per te
AstraZeneca

So far the project has had a great success, a large number of people have joined.
This counselling service is realized with the unconditional contribution of Astra Zeneca

Lupus UK shared a great poster on changing their regional groups' structure and increasing the organisation's reach and their volunteers, as a result.

**LUPUS
UK**

**New Coffee & Chat Groups
since December 2021**

Harrogate

Aberdeen

Pocklington

Fort William

Inverness

Goodmayes

Medway

Darlington

Leeds

Sutton

We switched from complex Regional Groups to simple Coffee & Chats, which attracted more volunteers to run the groups. The result is we can now reach people in areas where we have not been able before.



If you would like to attend or would like further information, please contact Alida at alida@lupusuk.org.uk or on **01708 731251**

Lupus Suisse shared a great poster on the organisation's concentrated efforts to overcome the language barrier they face in a multi-lingual country.



ELEANA (Hellenic League Against Rheumatism) made a poster on the organisation's many activities across the country and on the introduction of the first multi-disciplinary healthcare centre for RMDs in Kavala, manned by physician volunteers.

HELLENIC LEAGUE AGAINST RHEUMATISM ELEANA Katerina Rousa, Treasurer Hellenic League Against Rheumatism ELEANA



Annual Calendars

The Rheumatology Clinic of the University General Hospital of Larissa and the branches of ELEANA in Thessaly undertook a symbolic but essential initiative of social sensitivity and solidarity. ELEANA every year donates, gifts, such as handmade icons, calendars, to the staff of the Clinic, in recognition of their contribution to the optimal care of patients with RMDs from Thessaly and Central Greece, and its patients'.

This year the unexpected fire at the home of a family of five with young children in the community of Farkadona on the second day of Christmas led to a change of plans. It was decided that these calendars would be sold at a symbolic price and the proceeds from their sale would be donated to support the family who unexpectedly suffered.



Our story

Hellenic League Against Rheumatism was founded 45 years ago with the aim of offering and highlighting the problems of people with rheumatic diseases. So, until today, it has been working tirelessly organizing activities to inform and relieve these people, throughout Greece.



Our mission

Raise public's awareness about RMDs

Offer support to patients with RMDs and to their families.

Support research on the societal impact of RMDs and pain and cooperate with the scientific community

Advocate on behalf of people with RMDs especially with stakeholders and policymakers

Our Members and Volunteers

More than 9.000 members including people suffering from rheumatic and musculoskeletal diseases, Rheumatologists and HCPs interested in Rheumatism, Caregivers

Volunteers from all over Greece

Blood donation

A blood donation was organized in Patras, from ELEANA in collaboration with the local authorities to support the local community.



Multidisciplinary Center for RMDs Patients in Kavala

A new branch and the first model health care center was created by the Hellenic League Against Rheumatism ELEANA in Chrysoupolis, Kavala, with the support of the Municipality of Nestos. Stella Argyriadou, a General Practitioner, who, with the support of a multidisciplinary team of volunteers of different specialties, are supporting patients and their caregivers.

The main objectives of the Centre are to provide information, support, early diagnosis and personalised care. The services of the Centre are provided by all health professionals free of charge.



Physical activity

Self management is a concept we support by offering psychological support to our members as well as opportunities for physical activities. We offer sessions of Yoga, Tai Chi and swimming to our patients around the country (in Thessaly, in Patras and in Thessaloniki). We also have mindfulness sessions for people living in Athens.

Find us in Social Media:

Webpage: www.arthritis.org.gr / Email: info@arthritis.org.gr

Facebook: <https://www.facebook.com/eleanarheumatism/>

Twitter: <https://twitter.com/rheumatism78>

LinkedIn: <https://www.linkedin.com/in/eleana1978ath>

Lupus Belgium made a vibrant poster on the group's activities and on how the organisation helps lupus patients.



From **Lena Koskina** (Lupus Europe PAN) came a great poster on an online lupus community and on the sense of belonging.

THE SENSE OF BELONGING

A sense of belonging means, a kind of acceptance of one by a group.
 Belonging provides reassurance and security.
 It motivates us to share, coexist, communicate and create.
 We need, in a way, a safe framework for being and creating.

Volunteering can offer you a lot.
 In addition to the moral satisfaction you receive, you also feel the feeling of belonging.
 Being part of a group of people fighting for the betterment of this world, a group of people who share common ideas, values and aspirations give people the power to continue trying for themselves and anyone else.

You are not alone!! You belong with us!

TOGETHER WE GROW

A sense of belonging to a larger community motivates, improves our health and our sense of happiness.
 When we connect with others, we understand that all people struggle and face difficult situations.
 We are not alone.
 We find comfort through this knowledge.

HUG YOURSELF

With giving, not only you can offer monetary support, but you can also donate your time, which is priceless.

We are currently looking for some wonderful humans to work with us and bring to life projects that their community really needs.

For volunteering opportunities, please visit us.

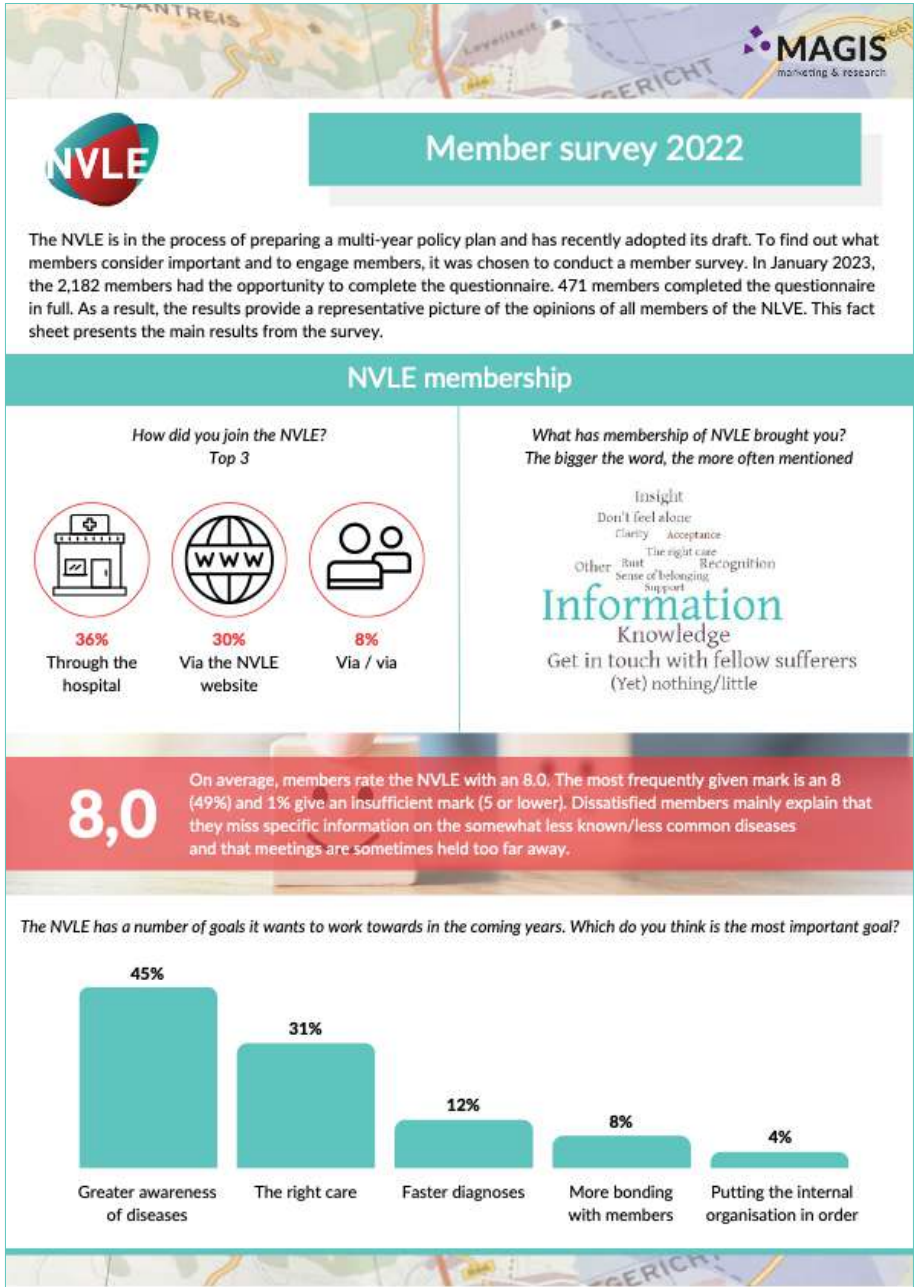
<https://facebook.com/greecelupus>
greecelupus@gmail.com

Greece Lupus

"I want to imagine a world where noone is alone. That a helping hand will always be there with empathy and open heart. Yes, we might not be able to belong everywhere but for sure we belong somewhere!"

- LENA KOSKINA-

NVLE made a wonderful poster on the results of their recent members' survey, which is part of their preparation for a multi-year policy plan.



CIB – Liga shared a poster with us on their very creative plan of ‘Going on Tour’, that is holding their monthly Board Meetings in a different city in Flanders and making themselves available afterwards to answer any questions from people.



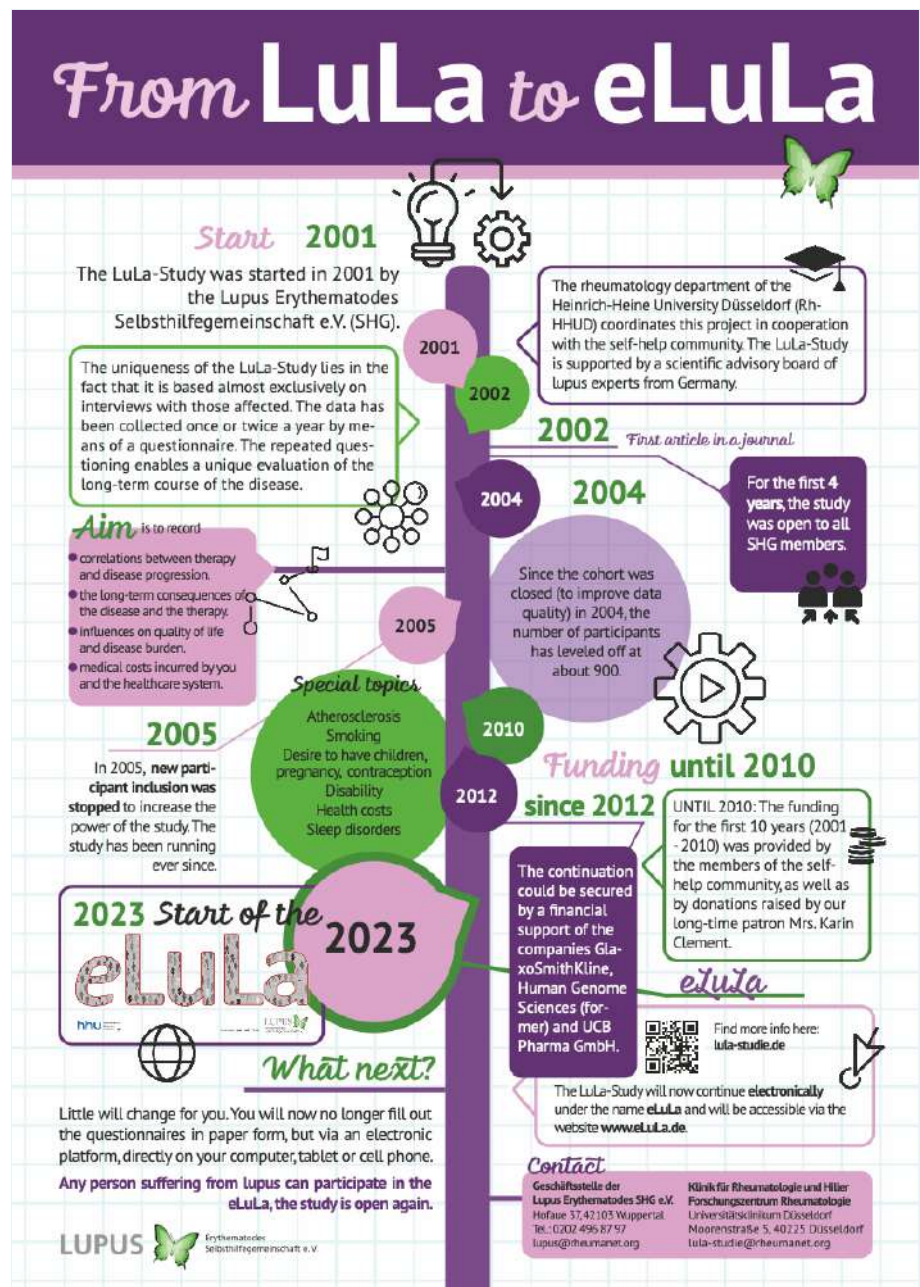
The Lupus Group of RRA Nadezhda presented a poster about their association's very creative photography project, 'A Bold Look at Yourself'.



Lupus Poland made a great poster about the organisation's varied activities, including trainings, campaigns, advocacy activities, webinars in 2022.



From **Lupus Erythematodes Selbsthilfegemeinschaft e.V.** in Germany came a fascinating poster on the evolution of the LuLa Study (that Lupus Germany started) to eLuLa, an electronic platform where the study can continue.



Kick Lupus

COMPETITION 2023

This year's Kick Lupus Competition was a very exciting one!

This year's competition was all about volunteering, and we had a number of incredibly good submissions on "How has volunteering for a lupus organisation helped change my life?".

The winner of the Kick Lupus Competition 2023 was announced at the Lupus Europe 2023 Convention. **Chryso Yiasoumi**'s essay was selected as the winning entry! In her essay, Chryso spoke about how volunteering for a lupus organisation helped transform her life by providing purpose, connection with others facing similar challenges, and the opportunity to make a positive impact on the lives of others. Through her involvement in a lupus organisation, Chryso found solace, improved mental health, and discovered a newfound sense of strength, resilience, and fulfilment.

To read Chryso's essay, click [here](#)



Organising Volunteering in a Member Group

by Alida Horne

Alida Horne, Lupus UK's Volunteer Coordinator, led this session. Alida discussed the importance of volunteers in Lupus UK, emphasising the need to treat volunteers with the same respect and consideration as employees. She highlighted the importance of getting to know volunteers and their motivations for joining the organisation in order to retain them. In Lupus UK volunteers perform various tasks, including hosting support groups, participating in research, and speaking to the media.

Alida highlighted the important role volunteers have in supporting Lupus UK and the different motivations and barriers volunteers may have. She emphasised the importance of communication and flexibility to encourage more people to volunteer and contribute to an organisation's work. The importance of support groups, effective communication, diversity, equality, and inclusion, aligning the motivations of volunteers and the organisation, making volunteering easier for volunteers, having a well-defined procedure for handling grievances and complaints, consolidating achievements, being agile and flexible, and encouraging volunteers to take on more responsibilities within the organisation were all discussed.

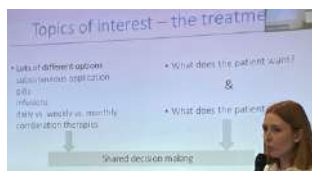
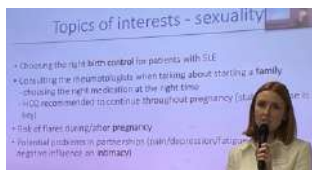
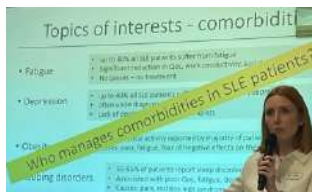
Alida talked to delegates about the importance of support groups for people living with lupus, highlighting the need for effective communication to overcome the idea of support groups being an "illness club" or "veterans club". For Alida, the benefits of support groups can be highlighted on social media to encourage more people to attend. The importance of encouraging volunteers and making it easy for them to take on more responsibilities was also emphasised.

Alida also discussed the need for volunteer training, conflict resolution, and dealing with difficult situations. The session covered a number of situations that may arise while managing volunteers in a charity organisation. One of the key aspects of managing volunteers is communication and having clear policies in place. For instance, if a volunteer expresses opinions that contradict the values of the charity, it is important to have information to back up the organisation's stance and to communicate this clearly to the volunteer. This can help ensure the organisation's values are upheld. In situations where there is conflict between volunteers, it may be best to listen to them separately, consider the situation, and then bring them together to have a conversation, encouraging open communication.

The importance of having clear policies and processes in place for managing volunteers was also stressed. Policies and processes include policies around financial payment, dealing with difficult situations, and having a buddy system or ethics committee in place to handle situations where there may be a conflict of interest. An animated Q&A session followed Alida's presentation.

My Experience with Lupus Patients in the Clinic

with Dr. Christina Duesing



Dr Christina Duesing joined the Convention as a young doctor specialising in lupus and ran a session for delegates on the communication gap from the doctor's perspective.

Dr. Duesing emphasised the importance of shared decision making and addressing symptoms such as fatigue, depression, and sleep disorders in the care of SLE. She also stressed the importance of discussing topics, such as sexuality and family planning, with physicians. Effective communication between lupus patients and their doctors is crucial.

Dr. Duesing went over what patients can do to bridge the communication gap and ensure they get the most out of a consultation; she discussed how patients can prepare for their specialist appointments, become experts in their disease, ask their doctors for help with specific issues and ask to discuss alternatives. The importance of lupus patients taking an active role in their treatment and the management of their disease was highlighted! Patients can take the lead and express their worries and needs to doctors. Dr. Duesing presented a checklist for physicians that may be used during appointments to ensure they consider the numerous potential causes of fatigue in lupus. Effective communication is important for optimal treatment as well.

Dr. Duesing covered how communication tools like fatigue checklists can make communication between patients and physicians easier and more effective. She emphasised the importance of physical activity in reducing fatigue and improving quality of life, especially for patients who are not physically active at the moment. Dr. Duesing noted that treating lupus requires a team of experts, including cardiologists, nephrologists, and psychologists.

The session then moved to the challenges physicians may face in a consultation, such as time constraints, changes in staff, and language complexity. It is important that patients ask for help and for other avenues to be explored to support their health, such as physiotherapy or psychological support. Patients always have the right to ask, according to Dr. Duesing! Dr. Duesing also mentioned how important involving a friend or family member in appointments to provide support and ask additional questions can be.

Communication skills were discussed and the need for more training for doctors on communication skills was highlighted. According to Dr. Duesing communication skills should be included in medical school and rheumatology curricula! Dr. Duesing recommended that patients who are unhappy with their doctor's communication style should try to address this (i.e. by discussing it directly with their doctor or even by lodging a complaint).

The importance of physical activity for patients with lupus was also highlighted. Physical activity can be seen as a form of treatment for lupus patients, but according to Dr. Duesing patients may often be embarrassed when doctors bring up the topic. A highly thought provoking Convention session, followed by an engaging Q&A!

Meet the Doctor

with Prof. Carlos Vasconcellos



Professor Vasconcellos, an internal medicine professor specializing in autoimmune conditions like lupus, was introduced. Professor Vasconcellos has been treating lupus patients for over 40 years and is committed to improving lupus care. The topic of the session was focused on understanding lupus, the use of steroids in its treatment and TOAD (term explained below). The speaker encouraged the audience to take notes and mentioned that there will be an open Q&A session afterwards.

Professor Vasconcellos began his session by discussing the complexity of lupus, referring to it as a puzzle. He mentioned that lupus patients can have various organ involvements, making it challenging to define the disease. He highlighted the heterogeneity of lupus and the need for better understanding of the disease. The discussion then moved on to the topic of remission and the difficulties in defining remission. Professor Vasconcellos mentioned different parameters for assessing lupus activity, such as clinical and serological remission, low disease activity, and active disease. He emphasised the importance of including patient perspectives in defining remission and acknowledged the disagreement among clinicians in this matter.

Professor Vasconcellos then covered the use of steroids in lupus treatment and the various levels of disease activity based on steroid dosage and clinical assessment. He presented a visual representation of the spectrum from very active disease to remission, highlighting the importance of assessing patients at each clinic visit and tracking their disease progression over time. Throughout the session, Professor Vasconcellos emphasised and re-emphasised the complexity of lupus, the challenges in defining and describing the disease, and the need for comprehensive evaluation and patient involvement in the treatment process.

The use of a system called TOAD (Total Activity Descriptor) for comprehensively evaluating lupus patients based on serology, disease activity, medication use, and clinical phenotype was discussed. The TOAD system can help doctors better understand their patients' disease courses and adapt treatment strategies accordingly.

Professor Vasconcellos emphasised the need for better and more adaptable treatment strategies for lupus, as well as a clearer definition of clinical phenotypes and their correlation with molecular functional science. The discussion then touched on the challenges of conducting clinical trials in lupus and the need for better characterisation of patients in order to evaluate treatment outcomes. Professor Vasconcellos discussed the SLE disease activity indexes, SLEDAI and BILAG which both assess various clinical and laboratory aspects of lupus to provide an evaluation of the disease. Validation of assessment tools was mentioned as an ongoing challenge, but Professor Vasconcellos noted the importance of using standardised criteria and measures across different countries for better comparison and understanding.

There are many treatments for SLE. Prof Vasconcellos focused on steroids as, in his own words, "Doctors know that patients have a bad relationship with steroids, and that is why it is important to have good information about this treatment".

[illegible][illegible]

- ▶ **Extended-spectrum penicillins**
 - ▶ **Physician and Patient compliance to steroid therapy**
 - ▶ smoking cessation
 - ▶ **Antibiotic prophylaxis**, less infection
 - less flares
 - less steroids to prevent infection induced flares
- ▶ **Hydroxychloroquine**
- ▶ **Immunosuppressives**: Azathioprine, MTX, MMF
- ▶ **Biological therapy**: Belimumab, Abatacept

- GC WITHDRAWAL IS AN ACHIEVABLE TARGET IN ALL**
- Patients who successfully stopped GCs had:
- Disease activity was significantly lower
 - Duration of remission was higher
- **1 report** (retrospective study of 122 patients from 22 countries):
- **1 longer duration of clinical remission (45 years)** with normal serology is associated with approximately a 375% likelihood of GC withdrawal
 - **1 significant proportion of patients are kept on GCs by their treating physician despite clinical remission**
 - If there is a history of severe organ involvement.
- serology emerged as the main influence for the physician's decision to withdraw GCs**

Glucocorticoids (GC) remain one of the cornerstones of treatment in lupus, and they are also included in the EULAR 2019 recommendations for the management of lupus. Prof. Vasconcelos informed delegates that data shows up to 88% of patients are treated with glucocorticoids and 57-86% undergo long-term treatment.

Glucocorticoids are an often-used treatment in lupus due to their anti-inflammatory effect, rapid mechanism of action, low cost and accessibility. However, as Prof. Vasconcelos says, “the only safe dose is 0”.

While steroids have many benefits for lupus, they also have many side effects. The hazard-ratio for organ damage due to glucocorticoids goes up according to the dose. According to Prof. Vasconcelos, data show that corticosteroid-related damage tends to accumulate over a prolonged disease course. Steroids have significant side effects, including changes in physical appearance, hypertension, diabetes, psychosis, osteoporosis, thinning of the skin, cataracts, glaucoma, and increased susceptibility to infections.

Interestingly Professor Vasconcelos told delegates that the use of methylprednisolone (MP) pulses over 1-3 days was preferable to high dose oral prednisone. More importantly Prof. Vasconcelos told delegates that glucocorticoid withdrawal and cessation can be achieved! Due to the long-term side effects and damage accrual of glucocorticoids, it is crucial to taper the dose as soon as the disease is under control, with the goal being withdrawal. However, this must be done carefully to avoid flare ups and adrenal insufficiency.

Steroids can work through genomic and non-genomic pathways, with different starting dosages and maximum dosages. It is important to find the appropriate role for steroids in lupus treatment based on patient risk categorisation and to involve patients in the decision-making process.

Withdrawal of steroids should be considered in lupus patients who achieve remission or low disease activity, but the decision should be based on both clinical and serological factors.

Serology, particularly complement levels (C3), can be an important influencer in the decision to withdraw steroids, but the field of serology in lupus is still evolving.

The role of other medications, such as immunosuppressants and biological therapies, should be considered to help reduce the cumulative dosage of steroids and minimize their side effects. It is important to note that immunosuppressants can be glucocorticoid-sparing treatments. The importance of individualised treatment plans for lupus patients was highlighted. Hydroxychloroquine was mentioned as a medication that is often prescribed to lupus patients. Alternative treatments such as other antimalarials, immunosuppressants and biologics like voclosporin or belimumab and Anifrolumab can also be effective in reducing the need for steroids in some cases.

Professor Vasconcelos concluded that there is a need for more research and discussion on steroid usage and tapering strategies in lupus treatment. The session ended with a very lively Q&A session with delegates.

Volunteering Handbook Presentation & Workshop Summaries

by Annemarie Sluijmers

In December 2022 a group of 17 dedicated volunteers began participating in the Volunteering Working Group to create a volunteer toolkit/handbook. The collected suggestions were gathered by the Lupus Europe Volunteering Working Group. A big thank you to all the work they already have done: Alida Horne (UK), Annemarie Sluijmers (WG Coordinator Lupus Europe (NL)), Lupus Europe (NL), Andri Nikolaou (CY), Charite Kjærside Nielsen (DK), Elina Eklund (FIN), Filipa Branco (P), Hrönn Stefánsdóttir (IS), Inês Ribeiro (P), Ingrid Hennes (Belgium), Jeanette Andersen (Lupus Europe (DK)), Lena Koskina (GR), Marga Schut (NL), Maria Olsen (IS), Metty Staal (NL), Nuria Zúñiga (E), Sabine Schanze (D), Zoe Karakikla-Mitsakou (Lupus Europe (UK)).

We had four online meetings. We have collected existing handbooks from Cyprus and Portugal, worked on various documents and created a draft handbook, with a solid idea of the content and the documents that should be connected to this handbook. We also created a volunteer pathway divided into three columns: *Recruiting*, *Retaining* and *Leaving*. This volunteer handbook, the collected documents and the volunteer pathway were the starting point for the various workshops we had during the Convention. The aim of the workshops was to collect information and use it to create more documents and solidify guidelines, rules, regulations, and bylaws to add to the draft volunteer handbook.

WORKSHOP 1

Recruiting & Retaining

The presenter discussed the challenges of recruiting and shared ideas from the group discussion on how to improve the recruiting process. The group identified the need for a coordinator to manage the recruiting process and they concluded that having a volunteering plan and a code of conduct for volunteers was necessary. The need for having detailed tasks for volunteers as well as specific deliverables was discussed. The group acknowledged the need for two different approaches – a task-oriented one and another approach that is more open-ended. The task-oriented approach could be more appropriate for new volunteers and the more open-ended one more suitable for those already involved in the organisation.

The group further discussed the need for mentoring and having a very clear list of tasks. They noted it was helpful to have a mentor assigned to every task, and that having specific and detailed tasks would make it easier for volunteers to decide which areas they could contribute to. It was suggested that the quest for new volunteers should be constant, not something that happens once a year, and that it is important to time looking for volunteers well. Having contests and making events like the General Assembly for example, more attractive, was also discussed as a possible way to make more people want to participate.

The idea of having as a last question to a survey for member organisations the question of “what could we do to make volunteering more attractive?” was discussed. Workshop members believed this could help Lupus Europe gain insights into what would motivate people to volunteer more. The group also suggested having an award for young doctors who volunteered. They noted that interviews with volunteers, already conducted by Lupus Europe and posted on social media, were inspiring and could serve as a good way to attract more volunteers.

Finally, the group discussed the importance of letting volunteers know their expenses would be covered. Some people may not want to volunteer because they think they would have to cover for their expenses. Letting people know their expenses would be covered could make volunteering more attractive to more people.

WORKSHOP 2

Leaving of Volunteers

Wendy (NVLE) led the workshop and feedback session on the issue of how to handle volunteers leaving an organisation. Different countries have different customs when it comes to dealing with different situations; for example in the Netherlands, when a volunteer leaves an organisation, they are given a gift card but no attempt is made to keep them if they have lost interest, as long as there is no conflict. Conflict resolution is the most challenging situation, and it may require bringing in a mediator to resolve. There should be documented bylaws and rules in place to deal with different situations, including privacy laws for which volunteers may need to sign an agreement not to divulge any confidential or private information.

Exit interviews should be conducted to understand why volunteers are leaving, and changes can be made to improve volunteers' experience based on feedback. Sometimes, volunteers leave organisations because of life changes, such as having children, and efforts should be made to bring them back later when those circumstances change. Guidelines, regulations, and rules should be developed on how to handle volunteers leaving and these may differ between Lupus Europe and national groups. Dealing with volunteers leaving an organisation might be a lot of work; having a process in place can make this easier to manage.

WORKSHOP 3

Selecting Volunteers

Ida Daiva Povilaite (Lupus Europe) introduced a visual diagram that outlined a four step process for inviting and screening new volunteers. The first step of the process was communication, where various channels such as email, SMS, personal communication, social media, and clinics were discussed. The content of the communication should be concise, clear, and aesthetically pleasing. In the second step, screening, volunteers' motivations, experience, disease acceptance, availability, and expectations may be evaluated. The third step involved a trial period to assess the fit between the volunteer and the organisation. Finally, a contract is signed if there is a successful match.

Ida invited comments from the team and summarised the main points discussed in their group's work on the four-step process for volunteer engagement. The importance of effective communication, motivation screening, and the trial period were emphasised.

WORKSHOP 4

Skill Development

In this workshop, led by Marlies (NVLE) the first thing that was discussed was the difference in skill development that may be needed for different roles: being a volunteer in research or being a volunteer in advocacy.

There are many volunteer trainings available. That includes trainings Lupus Europe may be able to recommend on a European level, or that national organisations may be able to recommend and follow. The trainings that may be followed by different volunteers depend on the interest, skill, tasks and capabilities of a volunteer.

Lupus Europe has a Patient Advisory Network (PAN). Members of the PAN have different levels of training and experience. In the Netherlands there is the *Patienten Participatie Commissie* (Patient Participation Committee). The possibility of Lupus Europe sharing online trainings with member organisations was discussed as was the possibility of member organisations sharing available trainings with each other. In the Netherlands there are special training programs with PGO, a national organisation which specialises in helping Patient Organisations in The Netherlands. PGO also organises the EUPATI NL training. EUPATI, EURORDIS and EULAR have trainings and they are available for volunteers to do. Sharing ERN Reconnet and PARE webinars as well as member organisation webinars could be useful.

In this workshop, the skills needed for a volunteer interested in research were discussed. They were identified as:

knowledge of

- the disease
- Good Clinical Practice

understanding of

- the results (analytic skills)
- English language
- the stages of medicine development

transforming

information to lay version, giving and getting feedback and not being afraid to ask questions.

The skills needed for a volunteer interested in advocacy were also discussed.

They were identified as:

- negotiation
- speaking in public
- knowledge of the disease
- social media
- knowledge of PowerPoint etc
- understanding landscape/stakeholders
- giving and getting feedback
- understanding Health Technology Assessment (HTA)
- not being afraid to ask
- translating information into native language

WORKSHOP 5

Reimbursement

Charite Nielsen (Lupus Denmark) led this feedback session and informed us that the workgroup discussed what expenses should and should not be reimbursed. Direct costs such as registration fees, travel costs, public transport and accommodation at hotels were included in the list of reimbursable expenses. However, indirect costs such as personal insurance and extra nights at hotels due to late arrivals were excluded from the list of reimbursable expenses. Travel insurance and car insurance, as well as alcohol, were also excluded from the list of reimbursable expenses.

The topic of pet care was brought up and, after a lively discussion, it was agreed that this is not an expense that should be covered by Lupus Europe. Travel companions were discussed, and it was decided that they should only be allowed for medical reasons relating to personal care or for mental health reasons, with proper documentation reflecting this. Childcare was another hot topic and, while it was generally agreed that it should not be reimbursed, there was an understanding that exceptions may be made in very specific cases on a case-by-case basis. The group emphasised the importance of diversity in attendance and inclusivity and there was an overall message of encouraging anyone with a barrier to participation or a question about reimbursement or a specific set of circumstances, to please let the Lupus Europe secretariat know.

Additionally, the group discussed the need to sometimes take distance into consideration and that may mean choosing for a specific event a volunteer that is closest versus someone from further away – assuming both people are equally qualified. The group also agreed that there should be a certain limit for reimbursable expenses, such as a set amount for tickets, and the rest should be covered by the attendee.

Overall, the group recognised the need to keep expenses to a minimum, while recognising volunteers shouldn't be financially burdened by their volunteering and while making attendance accessible to as many people as possible thereby prioritising direct costs that were necessary for participation. Indirect costs and expenses that were not absolutely essential to participation were excluded from the list of reimbursable expenses.

WORKSHOP 6

Code of Conduct

The workgroup had a very detailed discussion around Lupus Europe's code of conduct for volunteers; they methodically went through the document line by line, suggesting changes where they felt this was necessary. One of the key areas identified was the tone of the document, which participants felt was quite rule-oriented and strict. Participants recommended changing the language to a more partnership-focused tone. The first area of discussion centred around the section on respect where participants felt a line should be added to focus on respecting diversity of opinion and cultural differences. Removing a line around not breaking the law was also discussed and replacing it with a more general commitment to not breaking the law.

Participants emphasised the importance of including all appendices documents, such as the Data Protection Policy, the Equality and Diversity Policy, as part of the code of conduct for volunteers. They also discussed the importance of respecting confidentiality and obtaining approval before using any materials produced by Lupus Europe. The language of the document was discussed once more, with participants agreeing all sections should be written in a very positive way, rather than using language that could be perceived as negative.

The Conflicts of Interest Policy section was seen as very good, and here participants suggested only changing the language to focus on respecting and following decisions, rather than accepting the judgment of the Board or the Ethics Committee. They also suggested ensuring consistency throughout the document and avoiding duplicating the same idea in different sections. The need to clarify and specify what exactly volunteers should follow when it comes to Lupus Europe's direction was also brought up.

The participants also discussed the issue of online activity. They noted that the current code of conduct for volunteers requires all volunteers to seek permission before speaking publicly on behalf of Lupus Europe, but that this may not be practical in the era of social media. It was acknowledged that some organisations may still require permission to be given in such circumstances but suggested the Lupus Europe should consider whether such a requirement is practical.

WORKSHOP 7

Follow Up

The discussion centred on how volunteer follow up can be structured and organised. The workshop participants acknowledged that they didn't have any good examples of structured or organised follow up in their groups or a specific volunteer coordinator who is in charge of that. They then brainstormed ideas around this topic. The group came to the conclusion that a volunteer coordinator is essential to oversee the process.

An idea that was suggested was to create a list of volunteers. To create a useful list, participants suggested including details such as name, age, tasks that may be appropriate, skills, contact details and preferred contact method. They also recommended including a note on whether the volunteer is a patient, a doctor or has another role as well as noting when they were last active as a volunteer. Adding the date of when a volunteer was last active was thought of as particularly useful, as it could enable an organisation to order its volunteer's list based on the most active members when making phone calls or sending e-mails for events.

To encourage volunteers, the group discussed having thank you events and certificates to show appreciation and foster a sense of community. Optional meetings for volunteers held at least every three months were suggested. A discussion was had about how to handle ad-hoc volunteers who only want to volunteer or be asked to contribute in specific situations or specific events.

For inactive members, the group suggested making phone calls to enquire about why they hadn't been active and whether they still want to be on the volunteers list. However, participants agreed people who wished to remain inactive, should not be deleted from the list. It was also noted that for most organisations, the number of volunteers tends to decrease over time.

Overall, this reporting session highlighted the importance of having a structured and well-organised follow up system for volunteers. It was agreed that a volunteers coordinator was needed to oversee the process and that having a comprehensive list of volunteers was crucial. The need to show appreciation for the work of volunteers was also emphasised.

WORKSHOP 8

Motivation

Lena Koskina (Lupus Europe PAN) started this session by summarising discussions from the previous day, highlighting the importance of communication and the need for training and skill development among volunteers. Lena mentioned the challenges faced by volunteer teams, emphasising the value of mentoring and building trust within the team. How to involve young people was also briefly discussed, with the suggestion of organising more workshops and discussions to attract fresh ideas.

Delegates addressed the question of tracking volunteer inflows and outflows. They noted that percentages vary among different countries, with no definitive balance identified. The importance of volunteers having a clear understanding of their roles and managing expectations was emphasised, along with the need for flexibility and providing adequate training. Volunteer skill mapping and maintaining a balance between volunteer work and personal life were also identified as crucial factors.

The conversation then turned to the motivations that drive volunteers. Lena highlighted the significance of gratitude, and the impact of words like "thank you" and "I'm sorry." She stressed the importance of effective communication, valuing volunteers, and creating a sense of belonging within the organisation. Working group feedback emphasised the need to inspire volunteers through personal stories, providing feedback on their work, and demonstrating to them and to the wider community the impact of their contributions.

Feedback then moved to discussion of specific plans and benefits to motivate volunteers. As possibilities, tailoring communication styles based on individual preferences, utilising personal stories, showing the results of volunteers' work, and providing feedback to boost motivation, were all discussed. The significance of volunteers feeling valued was stressed; this contributes to volunteers' sense of belonging and commitment. Encouragement of continuous self-improvement through training and empowering others with knowledge was also highlighted as important.

The importance and significance of effective communication, motivation, skill development, and creating a supportive environment to engage and retain volunteers were discussed. This highlighted the need for clear expectations, recognition of volunteers' contributions, and continuous learning and improvement within the volunteer management process.

General Meeting

The General Assembly of Lupus Europe was held with 18 full members attending, on top of 2 associate members and the Board. While full minutes are available to members only, key highlights of this general assembly are as follows:

After having received the activity report from Jeanette Andersen (Chair) and the Financial Report from Alain Cornet (General Secretary). The assembly accepted with enthusiasm the application of “Udruzenje za pomoc oboljelima od reumatskih bolesti Crna Gora” (Association for help to patients with rheumatic diseases Montenegro) as associate member, and elected Annemarie Sluijmers and Ida Daiva Povilaite as board members for 3 year terms.

A discussion was held on how to better handle the issues of (relatively) informal lupus groups that are part of broader rheuma organisations. There was consensus that the board should present a proposal for amending the statutes so that such groups should be considered as associate members, unless they can demonstrate that they meet, on their own merits, the conditions set for full membership, in particular the fact that their delegate is democratically elected from within the lupus section.

The General Assembly also renewed the shortlist of potential Ethics Committee members. Finally, it was decided to hold 2 General Meetings each year. One (virtual) to approve the accounts and hold elections in March-June, and the other (face to face at convention) for further discussions on broader topics in October-November. This should allow for better organisation and distribution of the workload.

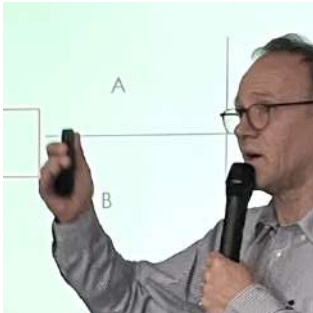
The Board also announced the intention of the General Secretary, Alain Cornet, to begin a transition to Zoe Karakikla Mitsakou to ensure better continuity of the association.



SOFT SKILL TRAINING

Thinking Styles

by Alain Cornet



The session was focused on the Hermann Brain Dominance Instrument (HBDI) model, which is a tool used to understand and assess the way people think and process information. Alain Cornet began with an introduction of the HBDI model and how it can be used to identify an individual's thinking style preferences. He explained that the model is based on the idea that different areas of the brain are responsible for different cognitive functions and that different people have a different natural tendency towards some specific styles of thinking.

Alain discussed the four quadrants of the HBDI model, which represent different thinking styles. These quadrants are labelled in colours: blue, green, red and yellow. The blue quadrant is associated with logical and analytical thinking, the green quadrant with strategic and organised thinking, the red quadrant with interpersonal and emotional thinking and the yellow quadrant with imaginative and holistic thinking. Alain explained that each individual can have a dominant thinking style, but they may also use elements of other thinking styles too.

The session then focused on how the HBDI can be used in a work context, particularly in terms of team building or problem solving. Alain explained that by understanding each team member's thinking style preferences, teams can work more effectively and efficiently as we learn to speak the other person's language. He gave examples of teams struggling with communication and collaboration issues and how by using the HBDI model and identifying each member's thinking styles, it is possible to develop strategies to work more effectively together.

Alain also discussed how the HBDI model can be used in leadership development. He explained that by understanding their own thinking style preferences and those of their team members, leaders can better communicate with and motivate their team.

During this highly interactive session, participants were also asked to complete a series of interactive exercises based on the HBDI model. These exercises were designed to help them gain a deeper understanding of their own thinking preferences, but also of how the HBDI model can be applied to different situations when dealing with people with very different thinking styles. By adjusting one's approach to better align with the thinking style preferences of another, it is possible to improve team morale, team dynamics and the effectiveness of communication.

Participants were given a number of set of cards to help them identify their thinking style based on the HBDI model. The cards were colour-coded to represent the four thinking styles: blue quadrant for analytical thinking, green for strategic thinking, red for interpersonal thinking and yellow for holistic thinking. Participants were asked to identify their dominant thinking by

selecting the cards they felt most comfortable with or that resonated with them the most. Once they had identified their dominant thinking style, they were asked to sit together in different tables that corresponded to their specific thinking style colour.

Alain explained that while the model can be a very useful tool to understand the natural thinking style preferences of another, it should not be used to make assumptions about someone's abilities or to manipulate people; it is important to always adhere to a strict ethical code when using the model. It is also important to remember that the model has nothing to do with someone's skillsets in communication; what it does measure is someone's natural thinking style preference.

Participants were then presented with a number of scenarios that involved interactions with people of specific thinking styles; they were asked to think about how they would best structure communication or an argument taking into consideration the thinking style of the other person. Participants were then asked what they would do differently if they knew the other person's thinking style was a different colour. This led to enthusiastic group work and a very interesting feedback session where it became clear that the way an argument or communication in general is structured does change significantly depending on the other person's thinking style preference.

Overall, this session was very well received by participants, who found it an interesting and helpful tool for self-reflection and personal development.



Closing

The closing session covered key takeaways and concrete next steps. Jeanette Andersen highlighted that delegates learned volunteering is similar on the national and international level. Through the Convention and workshops, it became clear that Lupus Europe needs a volunteer coordinator! Everyone was reminded that volunteering can have a therapeutic effect and be beneficial for volunteers! Different skills can be used for volunteering in different roles; everyone has something valuable to contribute! Delegates wished they had a doctor like Christina.

The interactive quiz for the strategic plan was very popular and may be repeated! Alain Cornet's session emphasised that having an organisation where people with different thinking styles come together is incredibly useful.

Delegates were asked to disseminate the information they received at the Convention in their national groups and encouraged to send Lupus Europe examples of how they did this, even if those examples are not in English. We still need your help to finalise the volunteer packs, so if you have been inspired by a workshop or would like to keep working on a particular topic contact Annemarie!

Two webinars are planned in the next 12 months. And for the first time, Lupus Europe will organise two separate General Assemblies next year; one in the beginning of the year and one in the end.

The 35th Annual Lupus Europe Convention 2024 will take place in....BRATISLAVA!