

In 1989, LUPUS EUROPE (then named ELEF)‘s first convention took place in the historical city of Leuven. 29 years later, LUPUS EUROPE’s 2018 annual convention brought us back to the place of our beginnings. The 2018 convention theme was “Restoring Hope”. Lupus is not always easy to deal with and we can often feel down: when a flare is painfully reminding us of the disease; when one more clinical trial fails; when we feel tired and misunderstood... As leaders in patient groups, we also regularly receive calls for help from people who are so scared after just being diagnosed, or who face depression. It is so easy to lose hope when you have lupus.... Yet there are reasons to keep hope: the search for new medication is more active than ever; patients are becoming more involved handling their own disease; lupus awareness is growing; legislation in support of people with disabilities (visible or not) is progressing; and patient support groups are bringing hope to their members in many different ways.



A total of 37 member delegates, coming from Belgium (5), Cyprus (2), Denmark (3), Finland (2), France (3), Italy (4), Lithuania (2), Netherland (3), Portugal (2), Slovakia (1), Sweden (1), UK (7), Switzerland (1), and Israel (1) joined the convention this year, making it a record number of participants.

*[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 in the restricted section of our website.]*

**Saturday, November 24, 2018**



**Opening session – Welcome**

Jeanette Andersen (Chair Lupus Europe) welcomed all participants, as well as the industry guests that joined us for the first day of the convention. As agreed last year, this year’s convention is shorter by 1 day. We used the day prior to the official opening for work-group member activities

Our Patient Advisory Network met for a full day, including a session supported by Wim Noel (Janssen) on Lupus and Ustekinumab (a drug that is moving in phase III) trial, looking at drug action mechanisms, Patient Reported outcomes, defining endpoints, ... in a very concrete way. They also discussed Patient Involvement with Rosanne Janssens, from EUPATI Belgium, and reviewed the work done by PAN members (Francesca on lay guidelines, Laura on patient Advocacy and Amy on Health Advisory Board). In the afternoon, the group split in two: A first subgroup worked with Wendy Zacouris on “HcQ survey”, and another one participated to a UCB specific workshop on patient reported outcomes. A number of non-PAN members also joined that workshop led by Thomas Morel (UCB) and provided feedback on best ways to measure patient aspects for which no biological measure exists, such as pain or fatigue.

In parallel, Jeanette Andersen, joined by Elina and Stalo, did a very intensive day of exercise. Indeed, last year, we presented and practiced exercises that can be used by any lupus patient (from being in bed till being



able to run and jump) to get back on a more active regime, as exercise is currently the only demonstrated effective way to combat fatigue. After validating the exercises with Marta Mosca (from Pisa University / ERN ReCONNET), we started production of the 5 small movies that will demonstrate the exercises and be available for broad distribution. With the help of Anne Charlet acting as Script and Coordinator, and of a professional camera / video production team, three of the five series could be recorded in one very intensive day.

Finally, our Friday was also the occasion for the “Message tracks” group to meet. After six zoom sessions and many “virtual contacts” amongst team members, this was the opportunity to finalize the three message tracks and the training that the team would present later in the conference.



After sharing the full agenda of the convention, where individual involvement and sharing will be the core component, Jeanette introduced our first speaker, Professor Frederic Houssiau, Chair of the European Lupus Society (SLEuro), Vice rector of the Catholic university of Louvain, and Leader of the European Lupus Nephritis Network.

**Restoring hope**

*By Professor Frederic Houssiau, Rheumatologist at UCL St Luc Hospital.*

*(More complete notes on Dr. Houssiau’s talk can be found in Attachment 1)*



While the fact that no new drug has been approved for lupus for so long can be interpreted as a lack of clinical progress, this is a very pessimistic look at the reality. The progress in lupus treatments has been and continues to be very encouraging, with falling mortality rates and a much better understanding of the disease that leads to substantially improved current care, there are many reasons to hope further improvement is coming. Professor Houssiau highlighted five key areas in the clinical domain that are very solid reasons to hope:

1. Better defined targets: We have now identified specific goals to be achieved through treatment that correlate with good long terms prognosis. For general lupus, this is the Lupus Low Disease Activity Score (LLDAS), for Lupus Nephritis, a proteinuria below 0.7gr after 1 year. Those goals help doctors adjust treatments with a clear end in mind, leading to better treatments and better quality of life
2. Better use of old drugs: Antimalarials are now much better used with a very high safety profile and a strong correlation with survival rate. Our better understanding of Glucocorticoids allows the reduction to no more than 4mg per day after 1 year (similar to Vasculitis) with 75% success rate.
3. The Euro-lupus regime allows tackling lupus nephritis without impacting the fertility of young women.
4. Multi-target therapies, combining several drugs that reinforce each other show very encouraging results, like the AURA clinical trial in which patients with the combination therapy had twice more remission after a year.

Lupus Low Disease Activity Status – LLDAS	
Asia-Pacific Lupus Collaboration	
1.	SLEDAI-2K ≤4, with no activity in major organ systems (renal, CNS, cardiopulmonary, vasculitis, fever) and no haemolytic anaemia or GI activity
2.	No new lupus disease activity (no flare) compared to previous assessment
3.	PhGA ≤1 (scale 0-3)
4.	Prednisolone dose ≤7.5 mg daily
5.	Well tolerated standard maintenance dose of IS drugs and approved biological agents

5. Moving towards personalized medicine: Even in failed trials, some segments of the lupus population have reacted positively, and might have succeeded if another endpoint (like LLDAS) had been selected. Those medicines, in some cases can be used “off label”, particularly where standard treatment has failed. The future of lupus treatment will be personalised medicine, where biomarkers linked to flares are identified for each patient, and treatment then can be targeted to the mechanism leading to that specific biomarker’s presence.

### **Restoring Hope?**

*By Bernadette Van Leeuw, Psychologist, Chair of Association Lupus Erythémateux (Belgium)  
(More complete notes on Bernadette’s talk can be found in Attachment 2)*

Bernadette started by challenging our convention title. Rather than a passive and simplistic definition commonly used for hope, she prefers a more action-oriented definition, as used in positive psychology. Hope is a way of thinking combined with an action to make better things indeed happen. Confronted with lupus, we are invited to accept the situation and then to give ourselves the right to consider positive developments and to act in that direction. She invited us to adopt an “intelligent optimism” approach, built of two-thirds of positive thoughts and a third for any negative thoughts... which allows us to remain realistic.



Bernadette identified four key reasons why many people with lupus often lose their capacity to have optimism: (a) a generalization of lupus flare symptoms, presented as permanent rather than flare specific, leading to a nocebo effect: the very idea that one should have pain is a formidable mean to actually have pain! (b) the requirement for doctors to insist on side effects of medication, making sometimes the patient more afraid of treatment than of her illness; (c) Patients doing well being silent on the internet; and (d) the presentation of lupus as leaving us powerless, omitting our means of possible action like adhering to treatment (the biggest cause for flares is non adherence to medication or treatments), or exercising (the proven way to reduce fatigue).



"An optimistic attitude towards life is the most powerful and least costly drug that human beings have ever had at their disposal.", says Th. Janssen, a Belgian surgeon turned to psychotherapist, but we also need to avoid excess, like the illusion that one could tame lupus just by optimism.

There is no magic wand to restore hope but there are practices that help, and others that hurt... and 3 different types of interactions that require different approaches.

To restore an individual’s hope, Bernadette advised us to first listen to the person, with respect, empathy and authenticity. Listening, acknowledging, reformulating, and being fully present and authentic with the person. After the time to listen, it is important to bring clear facts and figures about lupus, to remind people that statistics have no individual meaning. The question is to see what we can do to beat the odds. She urged us to be realistic and to explain that lupus will bring difficulties, time wasted in medical follow-ups, lots of medicines, but also that the likelihood is very high that the person will be able to adapt and have a good life.



Some people, regardless of the actual severity of their disease, are in such a poor mental condition that they simply cannot hope. We are not all-mighty, and it is important to remember your own self-care when supporting others who may be struggling emotionally.

We can build our own intelligent optimism, through methodical training to minimize our tendency to self-deprecation, anxiety and pessimism, and grow our own sources of satisfaction to build a life that fits us. It is important that we truly believe that there is a solution, even imperfect, to any problem. We have not chosen to have lupus, but we can choose our way of living with lupus and to look at lupus in another way, focusing on our possibilities, not on our limitations, becoming actors of what happens, not victims.



Bernadette gave us several suggestions of ways to build this, such as waking 30 minutes earlier to take ownership of our day and start it with things that we really like, to use visualisation techniques to fight negativism in front of adverse events, to give us SMART goals and build our self-esteem by achieving them, to exercise, or to surround ourselves with positive people and things that give us a smile.



Finally, she identified for us few things that we can do to build hope in our lupus communities, by creating an environment that helps people cultivate hope. Ensuring a 2/3<sup>rd</sup> positive stories in our publications, formally advising patients to consult only moderated groups if they want to interact on the internet, publishing positive stories of people that have lupus and managed to live in peace with the disease, ensuring intelligent optimists moderate our meetings, and reminding people that non-adherence to treatment remains the number one cause for flares

In closing, Bernadette urged us to find our own solutions to building hope, and to share them across countries so that the best ideas can be replicated across Europe.

### **Activity and work group reports**

After a well-deserved lunch break and a Mindfulness session, the work resumed with a review of activities done since the Milan 2017 convention. Jeanette Andersen explains that our presentation will be organized along the four strategic priorities of LUPUS EUROPE, each introduced by a 2-3 minutes video (available on the LUPUS EUROPE YouTube channel).

#### **Strategic objective 1: People with Lupus participate in, and benefit from, lupus research**

Kirsi Myllys, treasurer of lupus Europe and PAN steering member introduced the strategic element, highlighting that our priorities for last year were (a) to create the Patient Advisory Network, (b) to run a patient panel on youth, and (c) to relay research requests. All three priorities have been delivered, which is great. Kirsi explains that the Patient Advisory Network (PAN) is a team of 10 to 15 trained and energized Experienced Patients, living with lupus, appointed by LUPUS EUROPE that act as liaison and resource to value-adding scientific projects, Clinical Trials and other research related to lupus. They connect the patient community to the scientific



community, providing prompt, reliable and consistent advice and support from the very initial stages of research all the way to effective access through treatment plans. Two PAN members then brought personal insights into the program: Laura Sinnett presented her experience of joining the PAN, Francesca Marchiori explained how she participated to writing a lay version of guidelines on Fertility, maternity and menopause and solicited our support to disseminate ([https://www.eular.org/lay\\_recommendations.cfm](https://www.eular.org/lay_recommendations.cfm)) and Jeanette talked about her participation with two other lupus patients to the EUPATI training program.



Jeanette then debriefed the audience on the youth panel which took place in May 2018, bringing together 10 young lupus patients aged 18 to 27. This interactive workshop addressed



the key challenges that young people identified (such as taking pills every day, being understood by friends and families, and having to live with limits), the social life impacts of lupus for young people (including relationships & sex life, significant time off for medical procedures and the impact on ability to going out/drinking late with friends). They also discussed how they disclose – or not – about their condition, and the likelihood that they would consider participation to a clinical trial. A full report of this event is available on <https://www.lupus-europe.org/wp-content/uploads/2018/10/patient-panel-III-report-Final.pdf>.

Kirsi then explained the various surveys and studies handled by the network, including an ERN survey on patient education, a survey on Health Services in countries, and the Integrate survey on patient/doctor dialog. She gave a heads-up signal to members that a follow up to this survey should be arriving soon, and that we will also conduct an extension of the HcQ survey started by NVLE beginning 2019.

Finally, Wendy Zacouris presented the “fishbowl sessions” run in the European lupus meetings. In total, no less than 10 LUPUS EUROPE patient representatives have been part of these panel discussions, sharing point of views on topics as broad as “all lupus patients should be on antimalarials; improving trial design; B-cells depleting treatments or how to improve lupus outcomes”.



Strategic objective 2: “member organizations are enthusiastic and empowered”

After a short break, Katharine Wheeler, secretary - LUPUS EUROPE, then introduced the 2<sup>nd</sup> strategic objective “member organizations are enthusiastic and empowered”, highlighting our two priorities for the past year, a great convention and increased members’ engagement through networks, have both been delivered; She then highlighted that we are looking at expanding and have contacts with potential new members in four countries, a topic that will be discussed in the council, and then moved to presenting our new website, which contains a dedicated space, reserved to members, to foster collaboration and exchanges, as well as to support our work groups. Jeanette then explained that we have been very active in Facebook, Twitter, YouTube and the blog, four key advances that we can thank Katharine for, as she was the driving force of those implementations. We want to further develop cross-border collaboration



and do plan to have a minimum of two webinars next year to deliver that goal. The review of this strategy ended with Annemarie explaining that we had received a total number of 80 applications from all over Europe to take part in our working groups. This allowed not only the PAN, but also a work group on Communication,

one on developing Message Tracks, one on Kick lupus (see below), and the youth panel to get on track. A big thank you to members that have helped us research and create so many resources ready to be shared by Lupus Europe.

Strategic objective 3: Lupus Europe is heard and acting  
Annemarie Sluijmers (Trustee of Lupus Europe and member of the PAN group) explained that our key priorities were the renewal of our website, achieved earlier this month, and the development of 3 “message tracks” that can be used by our members to achieve specific goals. Handing over to the Message Tracks work group, Helga Ovens reminded us of the message tracks concept and methodology and then three message tracks developed by the team. The first is on how to get journalists interested in publishing an article on lupus (specifically at the occasion of World Lupus day). This message track will be extensively covered on Monday, with scenario and role play exercises. The 2<sup>nd</sup> is on having the GP bring the lupus hypothesis much earlier in the diagnosis sequence, rather than eliminate all other options first. The concepts here are



well established, but the question is now on how we bring it to life and act on it. Involving the ERN and the PAN will be the next step. The 3<sup>rd</sup> message track addresses the issue of having more people join non-invasive research or clinical trials to help advance new treatments. This message track will now be developed in a specific tool to be made available for members via our website. Moving on, Anne Charlet (Vice Chair Lupus Europe) then highlighted the very many events in which we have taken part, including (but not limited to!) a workshop on Clinical trials with DG santé and EMA, the collaboration with CME

forum to better educate doctors on patient involvement, the collaboration in two EULAR work groups, the work with EPF on Patient Advocacy summit, health technology assessment and the MedTech dialog, the roundtable with industry, the significant involvement yearlong with the European Reference Network ERN ReCONNET, including publication on unmet needs identified by lupus patients, and the active relation with SLEuro acting now as our Medical Board.

#### Strategic objective 4: Sustainability

Anne Charlet concluded on the 4<sup>th</sup> key element of Lupus Europe’s strategies: Sustainability. Significant efforts have been ongoing to establish sustainability of our operations. Our priorities were to build our sustainable funding and our secretariat and ensuring that we maintain a focus on Lupus and Europe. We seem to be on the right track, but in matters like sustainability, it is time to expand so next year, our goal will be to bring a 2<sup>nd</sup> part time person into our secretariat to strengthen the backbone of our operations, beefing up our presence in our home office of London. There is so much to be done, so we look forward to collaborating with all participants for a great 2019.

After a break for coffee, the group split to join the 4 available open space discussions forums. To make the reading of this report easier, we have grouped all outcomes of the various open spaces in a separate section further down.





### **Kick lupus**

*By Kirsi Myllys, treasurer Lupus Europe and Stalo Christoforou, Cyprus, member of the Kick Lupus jury.*

In Milan, we agreed that we should make Kick Lupus a recurring theme for the next few years, seeking ways to inspire people living with lupus to kick their lupus a little further away every day, by focusing on what they can do to achieve this. A team of seven was assembled and designed the 2018 Kick Lupus contest. They asked people with lupus to submit a word cloud showing how they kick lupus every day. The group received 35 great submissions, combining many artistic skills and insightful word selections. The winner of the contest was invited to the Convention. Kirsi presented a short PowerPoint animated clip with selected entries and then announced the winner, Sarah Woods, inviting her to present her word cloud.

Sarah's intervention was a very intense moment as she showed all the depth of her beautiful artistic work, a tree going from the roots of her disease to her most aspirational aspects. She told us of her late grandfather, diagnosed with lupus in the 70's and who passed away only a few years later at age 53, due to complications associated with lupus. Sarah's symptoms emerged in her late teenage years, but despite her frequent mentions of lupus as a possible cause for her many symptoms, she was only diagnosed earlier this year, resulting in her receiving proper treatment. She now feels so much better and can manage her full time NHS Mental Health Nurse job, whilst also being able to cope with caring for her three children. She feels critical that to truly 'Kick Lupus', timely diagnosis needs to be addressed. Participating to the word cloud contest also became part of Sarah's own healing process. She chose the visual of a tree, with strong roots providing stability, and with its associated notions of growth, life and renewal. Her tree is heart shaped, and its elements are interconnected so that it can thrive even if one of them would fail. She coloured the head of the tree person in a blue, as a reflection of her mood, and protected her from the sun with the leaves. She carefully placed the words in the tree associating their meaning to their place in the tree. Finally, she read a poem that she wrote (see annex 3) about how she felt in the prolonged period of getting diagnosed and taken proper care of.



A very emotional moment that ended with a standing ovation for Sarah and her beautiful work.

## **Sunday November 25th**

### **Council session**

The day started with the council session of LUPUS EUROPE. Detailed minutes of the council are available separately for our members. This report highlights key outcomes as available for a broader audience.

Kirsi Myllys, Treasurer presented the 2018 financial report, highlighting that 47% of our spending went to our first strategy (involvement in research), 26% to activities in support of members dynamism, 17% on our external representation, and 10% to sustainability focused activities. Through a quiz, the key numbers of the report were identified, helping to penetrate the reason for each significant cost. As we account on a receipt and payments basis, the timing of cashing grants is very important. This year, thanks to cashing a grant in the very last days of the



accounting year, we close with a net gain. The accounts were approved with unanimity. The council also delegated an auditor appointment to the board and confirmed unchanged membership fees for 2019.

Katharine Wheeler then led a discussion on “What is Europe”, a key question to meet our objective of one member in each European country but also to answer queries we receive from organizations wishing to be members or for surveys and contests.... After visualizing various possible answers, the discussion considered the desire to be inclusive... but also the risks of spreading too broadly. We are not the World Lupus Federation, and we need to focus on a reasonable territory for action...

The debate, and the subsequent vote concluded that

- (a) we should create a new member category, “friends of Lupus Europe”, which could be included in some of the projects, to share info, news, projects, ... and
- (b) that we should use the countries with territory fully in Europe or members of the EU as our full or associate members, while respecting no change in current membership, i.e. Israel will remain an exception.



New trustee elections saw the renewal of Anne Charlet and Jeanette Andersen mandates, and the addition of Laura Sinnott and Helga Ovens as new trustees, in replacement of Katharine Wheeler and Sara Badreh.

[The post-convention Board of Trustees meeting on Monday afternoon appointed Jeanette Andersen as Chair, Annemarie Sluijmers as Secretary, Kirsi Myllyls as treasurer, and Anne Charlet as Vice-Chair]

The council session was followed by an Open Space session with another 4 topics being discussed (see below)

### **Restoring hope**

*By Torben Wiese, Inspirational speaker from Habitmanager@*

It is impossible to summarize the presentation from Torben Wiese! Rather than a straight delivery of an intellectual message that can be captured in few points, he invited us to an experience of questioning our own habits and what they actually bring us both positively and negatively! In a positive sense by avoiding we spend huge amounts of time on making everyday decisions, but we also avoid thinking how these decisions – or habits - can limit us. We spend a huge amount of time making decisions in our daily lives but are our decisions – or habits – limiting us?



Habits influence our lives, our thoughts, our feelings and our actions. They somehow represent a “point of view” in the literal sense and prevent us from seeing other “points of view”. Habits can make us lose sight of what we are actually doing at the present moment. Changing habits and being present requires regular exercise, but also the conviction that it is worth the effort and the perception that there are other/better ways of doing things. Torben appointed everyone official “Change Manager”, inviting us to take ownership of our ways of living, to change the habits that don’t help us by adopting new habits that are more





productive. To do this, we need to have clear goals that we want to reach, and to live in the present rather than be stuck in our past or rushing into the future.

He also taught us the “NASA” model of engaging with people, which is that we should first identify the (N)



“Needs” of our counterparts and validate them through an (A) “Accept” testing before we define (S) “Solutions” that we can validate by (A) “Accept” verification. Too often, we offer solutions before truly understanding what peoples’ Needs are. If we define a clear goal, like having more volunteers engaged, jumping to solutions ahead of defining those volunteers’ specific needs will fail to deliver the appropriate results. Through multiple interactive exercises, alone, in pairs or in larger groups, participants went through discovery and practice of these key messages.

The rest of our afternoon program consisted in the 3<sup>rd</sup> wave of Open Space rotations and a summary of the 12 open space sessions for the benefit of the large group.

**Open Space sessions**

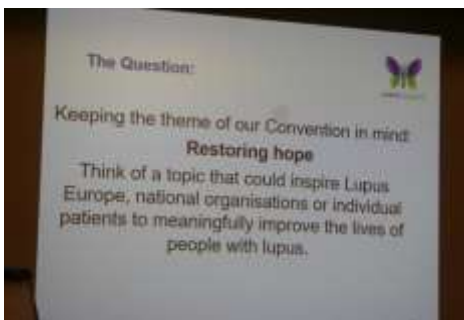
**Open Space**

Jeanette Andersen and Alain Cornet had the opportunity to participate to an Open Space event organized by Prof. Matthias Schneider before the Dusseldorf European Lupus Meeting. They both felt that the tool was incredibly powerful and engaging, and hence decided to bring the concept to the Lupus Europe Convention.

Open Space is a tool for engaging groups of people in discussions to explore questions or issues. At the start of the meeting, the agenda is an empty grid of timings and locations. The participants are then invited to propose the topics they would like to discuss themselves, in our case on the theme of restoring hope. Proposals are then assigned to locations and timings. Whoever wants to join each session can do it, and freedom is complete to change group at any point. Each person proposing a topic is responsible moderate the discussion and have notes taken to report to the broader group.



To optimize the agenda and ensure varied activities during the days, the open space time has been distributed throughout the convention. After an introduction to the concept and a time to propose topics on Saturday just before lunch, the first open session rotation, offering four topics in parallel took place Saturday right after the review of prior year results. Another session was conducted Sunday morning after the council, and a 3<sup>rd</sup> Sunday afternoon from 15:00 to 16:00. After these three rotations, the 12 topics discussed were presented to the plenum, and each participant was given three votes to select the four topics that would be discussed again on Monday morning, with a clear goal to achieve actionable next steps on those identified priorities. To make



the reading of this report easier, we have grouped the outcomes of the open space here, starting with the four selected topics that benefited from a 2<sup>nd</sup> round of discussions, rather than spreading the information based on the schedule.

### **More positive and valid social media (group D1, led by Katharine Wheeler, Belgium)**

Internet is an incredible source of influence, whether positive or negative, cheap, available everywhere, allowing dialogue and considered very relevant by patients. However, it carries today a disproportionate quantity of negative messages, jeopardizing its validity and its effectiveness in helping patients and their families. The group discussed the need for a strategy to shift internet from negative to positive, in line with Bernadette's "intelligent optimism" description i.e. with validated moderation. This would require having some type of certification of valid information and critical consideration of how open a group should be, e.g. how to manage online information with limited resources. They



also noted that humour can help get a more positive attitude and hence should not be disregarded. A special consideration should also be given to those people that are not on social media, ensuring that we avoid a strategy that would exclude them. Similarly, one should consider the needs of all ages and abilities to cover all aspects of social media. It was also felt important to decide where we post from. Open issues or challenges include the need for enough resources, particularly in small countries (any type of peer support possible?), the issues around translation and language, and the need to identify our own information sources: to keep the web valid, we ourselves

need to be up to date and to have a way of validating our own thoughts before sharing on-line.

As a concrete 3-year goal, the participants proposed to (a) create guidelines for us and member groups, (b) create a stamp (certification) for good sources of information and encourage each established member to mentor a newer member in social media. The specific next steps could be to distribute a social media toolkit (Nuryia Zuniga made one few years ago), to have a meeting of established organizations that have a good social media policy in place so as to build a "current best approach", and to create a group including patients, doctors (to help validation), graphic designer (to build a 'Lupus Europe' certified stamp) and possibly a marketing consultant. This team could then design and own a proper implementation plan.



Team members (Ines, Charite, Catherine, Kirsi and Katharine) expressed interest to actively work on this project.

### **Lupus Success stories (group D2, led by Sylvia Gäumann, Switzerland)**



We hear too many bad stories, not enough positive ones because "a falling tree makes more noise than a growing forest". To spread hope and positivity, to fight alarmism, and to switch the thinking to today's reality of better lupus outcomes, spreading positive stories to the patient community is a critical need.

The group discussed how positive stories can help fight traditional and outdated views of lupus, as well as preconceived ideas. It can help people cope with lupus and get on a path of success and evolution (both social and professional) by showing "role models" that would be sufficiently approachable, yet ahead of our experience. It also would be a great way to highlight the value of the writer as a person. We need positive stories to counterbalance the negative ones and bring

hope and inspiration to people with lupus.

The group identified as a 3-year goal to have 50 stories of patients with a positive angle, from all over Europe, available for all members to use. To collect the stories, they suggest a competition (possibly under the Kick



Lupus theme) for the best lupus stories with a positive tweak. To succeed, we need support from local organizations to disseminate the information and “advertise” locally, and from LUPUS EUROPE to offer a trip to the next convention as first prize. We could also think at publishing the stories “as a book”. The first next steps include defining the competition rules (defining maximum length, allowing pseudonyms, consent to use the stories, timings, ...). The question of whether countries should do a first filtering and organize the translation of the best texts is to be debated. A social media campaign, or posters in rheumatologic clinics might further help. Issues

identified for the organization is foremost language (could countries help with translation), and to a lesser extend funding and creation of a tool to collect the stories. Team members (Margarida, Sandra, Sharon, Simona and Sylvia) are all eager to help.

### **Lupus Patient Led Research (group C1, led by Laura Sinnett, UK)**

The group identified how patient-led research reflects and indeed meets the need of ensuring the experience of being a patient with Lupus is heard. People with Lupus can often understand the varying complexities of their condition in a different way to how an academic or doctor may understand the disease. By building patient-centered relationships within health care communities, their personal insights and perspectives on how to manage their symptoms or enhance their quality of life can lead to adjusted priorities and feed the continued cycle of research. There remains so much about Lupus yet to be discovered and understood. We asked ourselves, “What areas of Lupus would benefit from additional research?”. The team quickly produced a list of questions such as: Is Lupus more prevalent in some geographical areas in a given country, and would that then be explained by genetic, or environmental factors? Is there any link between gastrointestinal findings and Lupus triggers and manifestations? What are the best drugs to treat different variations of Lupus? Could stem cell & plasmatic therapies work for Lupus? What other diseases have overlapping connections with Lupus?



The team discussed the need to be more ambitious in the challenge to gather support from pharma industry and regulators and in achieving academic evidence to motivate healthcare professionals to place Lupus at the fore of research. Empowering people with Lupus to get behind such a drive via patient organisations in



our own and other countries is a great method to signpost and work together for one common goal. The identified first next step is to put forward a strategy statement that is clear and accessible. Then, it will be necessary to work with Industry and Academic networks to bring some of the ideas identified by the participants on their agenda. To make any impact, local and national governments, EU and global leaders would need to be lobbied for support with an ultimate aim of sharing and then putting the research results into action.

The group which included current members of the PAN is highly motivated to progress this issue. The insights of Valerie Belsack (pharma rep, already actively runs global Lupus research trials) have been highly valuable and show the benefit of working such issues in partnership. Many individual country projects are already identified or in motion. The PAN Steering Committee and PAN members will be ideally placed to drive those projects (and more) further.

**Enjoy little things and “Get out”** (combined groups A3 led by Annemarie Sluijmers, Netherlands and C3 led by Helga Ovens, UK)



Both groups, starting from a different idea (getting out into nature and enjoying relaxing with inexpensive activities) came to similar conclusions of their benefits so decided to merge. Going in nature or enjoying the small things in life – both requiring you to be present (referencing Torben Weise’s presentation) - are inexpensive and always available things that we can do without much preparation or scheduling. They are activities that can improve our morale and health



(through walking, getting fresh air, meeting other people, observing wildlife, listening to the birds etc ...) without requiring costly equipment or resources. By being in the “present moment”, this reduces anxiety, worries and stress. It works a bit like mindfulness, bringing energy, happiness and not imposing pressure to achieve results: the only focus can be “feeling good, being well”. Getting out can be done alone, but also with family and/or friends. The key challenge is often in ourselves as perceived urgent duties keep us from doing “little things”, so finding friends or an alternative motivation can help us get moving outside is a real help. An obstacle to getting outside within our groups is geographic proximity of members, but our organizations can inspire individuals to organize their own small events, walks or simply by just encouraging others to enjoy nature.

In term of 3-years plan, the group felt it would be easy to produce a ‘Nature Pack’ with checklists, examples, etc for groups or individuals to use. Included could be “green cards or green prescriptions”, i.e. 5 vouchers contained in the pack which requires the owner to commit to taking for example 20 minutes in the fresh air, a meeting outside instead of inside, 10 minutes just to sit and listen. This could be prepared by the next conference. Year 2 and 3 ideally would be evidence based to finally conclude with a piece of work proving – or not – the benefits of nature on our well-being and management of Lupus. All members of the group felt nature was important and often missed when juggling lupus and our daily lives therefore offered collaboration should any future work develop in this area. Sarah and Helga concluded saying that as they live only 20 miles apart, will meet up soon for some outdoor art sessions.



Community events (group B3, led by Sharon Ram, Israel): The group emphasized the importance of meeting the community via “real” events, allowing to share experiences- and meeting families; the human contact with real people is vitally important. Such events also spread awareness of lupus and allows us to develop our knowledge of the disease. Community events help us to discourage any isolation people may feel, offer opportunities to make new friends and to gain attention from stakeholders like industry, clinics and/or potentially the media. The key issues identified are the feelings of shame that prevents some people from participating in such events.

Fill your day (group A2, led by Chryso Yiasoumi, Cyprus): Doing things during the day makes you feel better.



Being busy prevents you from focusing on your problems and gives you positive energy. It connects you to other people and gives you a sense of achievement as you see the results of your day when you look back. As such “doing things” breaks the depression cycle, it gets you out of the house, helping to socialize, and bringing new learning. This proactive approach, versus the passive “I can’t do anything” is a crucial way to be positive. You take charge of your life and maintain or grow your social network. The key challenge is that you need to make it happen, i.e. inject energy at the start, to be motivated... the true value appears only at the end of the day, but it is worth it!

Connecting (Group B2, led by Daniela Rava, Italy): connecting the SLE community is crucial to share information. Social meetings, using Skype, WhatsApp, etc. are a great way to stay connected. It allows people to share experience, but also medical information, to compare country by country, to exchange new ideas, and to empower ourselves for action. We feel part of a community and can better face life and situations that develop. As a result, it improves our quality of life. The challenges are to organize such connections across countries, in a more reliable way than forums, while still being open to people we do not know (yet).



Organizing handicrafts workshops (Group A1, led by Helena Hedencova, Czech Republic): handicrafts and



hobbies help us relax and build social contacts. Being all together in the same room, working and giving advice to each other, we create friendships but also an informal support where we can talk about many things. It helps us to forget about the illness and the pain, feeling better while in contact with other people, learn new skills, and importantly, distracts our minds. When we work on handicrafts together, we belong “somewhere” and are no longer “patients”, but friends like “normal” people are. Implementing a local handicrafts workshop is not easy, because you need to have enough people coming. Some need to be ready to share their hobby with others, others need to be ready to take an interest into a new hobby. It takes someone to organize and motivate others to come, and some small investment might have to be found to buy tools or materials. Also, in some

cases, you need to find a venue, which is more complex when you also have disabled participants.



Creativity and Stress Reduction (Group B1, led by Sandra Dahlberg, Sweden): Creative activities are important to help reduce stress, transferring the pain and distress into positivity by distracting from the pain and disease. When you brainstorm for example, your anxiety goes down, and your brain fog evaporates as you interact with others in a positive spiral. The participants exchanged their experience on the subject, and concluded that next to face to face meetings, this can also work in webinar groups, social media, community links, as long as there is direct people interaction. Implementation of such a program however requires having a large enough group of interested people, managing time zones and languages, and having proper support tools.

Two topics were offered for “open space” discussions by the board to collect input on questions relevant to LUPUS EUROPE and orient the board action.

1. Should Patient experts be paid? (Group C2 – owner Kirsi Myllys, Finland):

Over the past year, we see a definite trend in pharma companies offering to pay individual patients (on top of cost reimbursement) for services and time they give in support of industry specific meetings such as participation to health advisory boards, ethical boards or to review clinical trials documents or design. This trend has a very positive aspect, the recognition that patients are “equals at the table”, where other participants are typically paid, so it does bring “external equity”. It compensates for the time-consuming task and the possible lost income taking time away from money earning activities. However, it also creates a divide in the patient groups, introducing an “internal inequity” as the patients involved with pharma could get an income for their time, while those performing other tasks, such as receiving phone calls of newly diagnosed people, writing newsletters, serving on the board, ... might spend even more time but remain true unpaid volunteers. This internal inequity could be very dangerous for patient organizations over time as the most dynamic volunteers could prefer the “sexy” and paid patient expert roles, leaving the central patient and organization support roles unstaffed. The group discussed relevant aspects such as the need to define who is paid, who is not, the funding of the PRP/expert patient training (realizing it could lead to a long-term income). The impact on volunteers could be very significant. The discussion also highlighted that in some countries, patients that benefit from social support cannot receive an income from such services, to the risk of losing their benefits. Some of the group members highlighted that it would be great if all volunteers could earn some compensation for the time they give to the charity, but others argue that this is then losing the essential concept of gratuity, at the core of a charity, making the patient organizations a kind of business, and distracting funds from other support activities that are much needed.



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2. What topics for World Lupus Day? (Group D3, led by Anne Charlet, France):

Two years ago, Lupus Europe made the conscious decision not to run a European WLD campaign, but leaving members the choice of running a local campaign (with possible synergies amongst members interested) or adopting the World Lupus Federation (WLF) campaign.

A few weeks ago, the WLF asked us if we would have ideas of a theme for next year(s) worldwide campaigns. The group appreciated getting the opportunity to suggest topics, and the benefit of having a united campaign, particularly as this helps small members pick something that has been largely developed already, and just localize it for their country use. The group then moved to a brainstorming of possible themes. From the large number of suggestions, the following were highlighted: “world, can you see me?” (insisting on the invisible aspect of the disease), “the floor is yours” (making lupus the centre stage), “seeing the possibilities”, “live the possibility, be the possibility” (insisting on the power of patients to do things rather than being victimized), “raise your voice for lupus” (a call for action), “break free” (a call for not being a victim, but a winner, an achiever), “Embrace your inner lupus” (focused on acceptance, which allows to start rebuilding ourselves), and finally “lupus does not define me”.

This last proposal won by far the biggest consensus from the convention participants. It reflects the deep desire to be accepted as we are, which is a lot more than lupus, not to be reduced to our disease dimension which then becomes the focal point of all discussions, concerns raised (even to be friendly), but build a cage around people living with lupus by defining them on only one dimension of their lives, and one which they would like to escape more often...



In the evening, participants walked to the historic city centre of Leuven for a group dinner. Some selected a longer tour, visiting key landmarks of the city, under the direction of Ingrid Hennes, Chair of CIB Liga (Belgium), others took a shorter one, still benefiting from views of the old city.



### Monday, November 26

The day started with the final round of open space, working on the four topics selected by the group as mentioned above.

#### **PARE and Lupus**

*By Nele Cayers, Chair of PARE and lupus patient*

Nele introduced us to the world of PARE, the People with Arthritis/Rheumatism in Europe. This is the patient leg of EULAR, the European League against Rheumatism. PARE comprises 36 member organizations (covering rheumatic conditions in their respective countries) as well as Co-opted members (which are disease specific international organizations). Like Lupus Europe PARE is represented in the Executive Committee of EULAR. Its objective is to create alliances and networks of user-led organizations, raising awareness on Rheumatic and Musculoskeletal Diseases (RMD's), enhancing patient participation, and making a meaningful difference in the quality of life of people living with RMD's.



Nele urged us to use the various PARE resources, which are available directly or through member groups. As example of direct support, she mentioned the Newsflash E-Breakthrough (to which all can subscribe), the activities around World Arthritis Day and the Don't Delay, Connect Today Campaign (which will focus on Work next year), the Annual European Congress of Rheumatology (in which sessions are dedicated to patients under the PARE program) or the Young PARE group for people from 18 to 35 years of age.

Other supporting activities can be reached via LUPUS EUROPE, such as the Knowledge Transfer Program (a fund available to foster cross border exchange of best practices) or the Annual European Conference of PARE (a two days training program available to a limited number of patients). This program can also be accessed via the National Member organizations. Finally, the Stene Prize (accessible via national groups) is a key source of inspiration every year.

Nele encouraged patients and relatives to propose posters and write abstracts for the next EULAR congress, which will take place Mid-June in Madrid. This is a great opportunity to showcase our groups' great work and to influence the future direction of patient organizations. On website, those who may be curious about



submitting an abstract will find templates and guidance on the process. This again was promoted by Nele. Deadline for submissions to next year's EULAR Congress is January 31<sup>st</sup>!

**Working with media Workshop**

By Sylvia Gäumann, Switzerland, Member of the “message tracks” working group

Sylvia shared her experience of working with Journalists. If we want to have an article published in their media, we need to start with an understanding of their needs. These will typically include stories relevant for their audience, a human touch that people can relate to, a news hook or special angle (sex and crime work very well... but maybe not for lupus), facts, figures and a reliable background coming from trustworthy sources. Day by day, journalists face the challenge of time pressure due to the need to produce faster and more, but also an immense information overload. An average journalist gets more than 100 press releases a day, in addition to countless news from news wires, online media, etc. It might hence be advisable to contact journalists in the summer period, where they lack stories. Journalists are also confronted with fake news, so being able to show our credibility will be important.



In this context, our challenge is to be heard in the news universe. This requires making lupus attractive enough for the media. Lupus is not well-known, so why should a journalist talk about it? Our opportunity is to find the right hook, and the right journalist, taking the time to build the relationship and the stories. We need to tailor our communication to the needs of the journalists... so to the needs of the newspaper audience.



We can also turn some of our challenges into opportunities: lupus is not well known? Great, that means we have something new for you... the journalists don't have much time? Great, we have a ready and appealing rough story line that they could easily integrate in their report. They want some local stories? Great, we have local patients...

Sylvia then moved on to the specific message track developed to “sell our story” to journalists. This is a one pager that brings together the key selling lines and supporting arguments to convince a journalist to publish an article on lupus. It focuses on three key items: (a) We have an appealing story for your audience, (b) we want to raise awareness of lupus, and (c) you can make a difference for patients and those not yet diagnosed.

After explaining the message tracks, the group split into four groups which practiced it through role play. Each group got assigned a specific newspaper, so that participants could think of how they would tell the story to different media differently: The Sun, the Financial Times, Women's Health and the local city gazette. Each group was asked to first identify three things that their newspaper audience liked, then develop a desired headline (creative suggestions included “your neighbour might have lupus”, or “lupus means money”, ...), then selecting the best supporting reasons and facts, and preparing the discussions around them. After an exciting 25 minutes role play and analysis, the groups came back to the plenum to share their experiences.







Most groups identified identical key learnings.

First and foremost, the need for preparation. Having readymade sentences so that you do not need to search for your words, a list of arguments, having the things clearly written, not assuming you will remember, and rehearsing with someone, several times.... Second, the need for persistence in a polite way. Don't let yourself be put off or discouraged. Be calm but insist. Finally, it is hard to get convincing arguments when the journalist pushes back, so you must have a very compelling story ready.

Sylvia concludes this great training with few hints: Identify one person in your organization to deal with media, and have that person start small (district/local/free community press). Localize the story and tweak it to fit the target media's audience and start well in advance of your target publication date.

### **Close of Convention**

After a big round of applause for what will be confirmed in the evaluation as the best session of the convention, Jeanette Andersen closed the convention, thanking all participants for their enthusiastic participation through the end, despite a heavy program. Brexit or no Brexit, we remain united, and as a clear sign of this continued collaboration, our next convention will take place end November 2019... in the UK!



## **Annex 1 - Restoring hope**

*By Professor Frederic Houssiau, Rheumatologist at UCL St Luc Hospital.*

While the fact that no new drug has been approved for lupus for so long can be interpreted as a lack of clinical progress, this is a very pessimistic look at the reality. The progress in lupus treatments has been and continues to be very encouraging, with falling mortality rates and a much better understanding of the disease that leads to substantially improved current care, and many reasons to hope further improvement is coming. Professor Houssiau highlighted five key areas in the clinical domain that are very solid reasons to hope:

1. Better defined target: In many diseases, targets for treatment are well defined. For example, in Hypertension, we know that if you reach the target of 130/80 mmHg, people will do well. In lupus, it is much more complex, and absent a target highly correlated with long term outcome, how to validate that a treatment plan really works? There has been huge progress in this area, with the development of LLDAS (Lupus Low Disease Activity Score), a Physician Global Assessment (PhGA) of disease activity, which correlates with long term outcome. Patients reaching LLDAS 50% of the time have 50% lower damage accrual after four years and report a significantly higher quality of life. In lupus nephritis, reaching a target of less than 0.7gr. proteinuria after 1 year brings a 94% probability of having a normal renal function after 10 years (missing it results in a 33% risk of renal failure), and thanks to the very long term follow up of patients in University Hospitals, we continue tracking this to establish the validity of this target to predict positive outcome after 20 or 30 years. Better defining targets is a huge improvement as it drives appropriate changes in treatment follow up.

### **Lupus Low Disease Activity Status – LLDAS** Asia-Pacific Lupus Collaboration

1. SLEDAI-2K  $\leq 4$ , with no activity in major organ systems (renal, CNS, cardiopulmonary, vasculitis, fever) and no haemolytic anaemia or GI activity
2. No new lupus disease activity (no flare) compared to previous assessment
3. PhGA  $\leq 1$  (scale 0-3)
4. Prednisolone dose  $\leq 7.5$  mg daily
5. Well tolerated standard maintenance dose of IS drugs and approved biological agents

2. Better use of old drugs: While we still use old drugs, we do it in a much better way than before. Survival rate of people with lupus nephritis, for example jumped from 50% at two years in 1950 to 90% at 10 years in 2010... so that is before biologics were approved for lupus nephritis. Hydroxychloroquine (HcQ), has for example long been used only for mild forms of lupus, because we did not know the action mechanisms, and hence thought it could be eliminated when “stronger” drugs were used. We now know it is a type 1 interferon regulator that should be used for all people with lupus. Its safety profile is very high, and it is the drug that is most correlated with survival rate in lupus. We also now understand how reduction of Glucocorticoids relates to damage accrual. This knowledge is driving treatment plans to move patients to 4mg max per day after one year, similar to what is done in Vasculitis. It does not work with everyone (75% success rate), but it should be tried with everyone.

3. The Euro-lupus regime has no gonad toxicity: In the Euro-lupus regime, treatment is induced with low-dose intravenous cyclophosphamide (6 x 500 mg IVCY q2w). The treatment works very well in most cases, and importantly, studies have now shown that this treatment regime has no gonad toxicity. This is a huge improvement for young women. Studies demonstrate that the anti-Müllerian hormone levels of women having received less than 3mg or between 3 and 6 mg of CYP are the same as those in the general population, so we now have an induction treatment for lupus nephritis that does not affect fertility.

4. Discovering effective multi-target therapies: the idea is that we should combine several drugs at induction. Instead of taking one drug or another, as was done historically, we are now looking at combining several drugs. An example is the combination of Voclosporin with MMF (Mycophenolate). Next to its calcineurin inhibitors blocking IL2 role, Voclosporin also stabilizes podocytes, which are cells that are protecting glomeruli, the key units of the kidneys. The phase II trial worked very well, comparing MMF + Voclosporin to

MMF + placebo, and implementing a fast reduction of Cortisone, patients with the combination therapy had twice more remission after a year.

5. Moving to targeted therapies and personalized medicine: Over the past years, plenty of trials, targeting plenty of different mechanisms of the lupus vicious circle have failed. The only successes have been the BLISS (Benlysta) ones. But several of those “failed trials” indicate positive results in some segments of the patients.

Epratuzimab failed in phase three so did not get a label, but maybe worked. Rituximab (Mabthera) was repeatedly tested in lupus nephritis trials, always failing the primary endpoints. Yet, when lupologists used it for years with patients where everything else had failed, they obtained success in some 50% of patients! Today, many doctors use it “off label” in clinic, where it is legally allowed, because it works. It is not the first level drug, but possibly as much as 5% of people with active lupus around Europe receive it.

Target	Molecule	Trial acronym	L/LN	Phase	N	Results
B	Rituximab	EXPLORER	L	II/III	257	No benefit
		LUNAR	LN	III	144	11% more responders RTX but NS
	Ocrelizumab	BELONG	LN	III	381	Early terminated - Infections
	Epratuzimab	ALLEVIATE 1/2	L	II	90	Early terminated - Drug supply
		EMBLEM	L	IIb	227	More BICLA responders
		EMBODY 1/2	L	III	1574	No more BICLA responders
T	Abatacept		L	IIb	175	No less BiLAG A/B flares
		ABATACEPT Trial	LN	II/III	298	No more renal remission
BAFF	Belimumab	BLISS 52	L	III	865	14% more SRI-4 responders
		BLISS 76	L	III	826	9% more SRI-4 responders
		BLISS SC	L	III	836	12% more SRI-4 responders
	Bisibimod	PEARL	L	III	547	No more SRI-5 resp w24
	Tabalumab	ILLUMINATE 1/2	L	III	2288	No more SRI-5 resp
	Atacicept (+ >APRIL)	ATACICEPT Trial	LN	II/III	8	Early terminated - Infections
IFNα	Sifalimumab		L	II	431	14% more SRI-4 responders
	Anifrolumab	MUSE	L	II	305	17% more SRI-4/OCS taper responders
	Bortezomib	ROSE	L	II	238	More SRI resp if ≥10 pred w0
	INF Kinoid		L	III	28	Down-regulation of IFN signature
IL6	Sirukumab	SIRUKIMAB Trial	LN	II	24	No more renal responders
Tweak	BIB023	ATLAS	LN	II		Trial stopped interim analysis

The question of stem-cells is raised. Professor Houssiau answers that Hematic Stem-cells treatment

worked in Systemic Sclerosis, but the problem is that you have 10% treatment related mortality... Placenta cordon stem-cells have different properties with regards to immunosuppression. And results have been surprisingly good, but the trials were not controlled, so it is difficult to use them as only base. Proper trials are in the pipeline, but with a low number of patients.

Recently, Anifrolumab was good in phase II, failed in one phase III... We are now awaiting the 2nd phase III that is still going on. The question must be raised of why so many trials fail. There might be an aspect of defining the right endpoints, due to the complexity and high variability of symptoms. Professor Houssiau makes the hypothesis that if we would have used LLDAS instead of other criterions, many trials would have worked. There is also the question of too much Glucocorticoids and immunosuppressant being given in the trials “base line”, as it is very difficult to prove superiority when GC mask all short-term effects.

Precise medicine is what will make the difference in the next 10 years. No one drug will work for all, as is the case in rheumatoid arthritis. Today, we cannot anticipate who will respond to what drug, but the increasing availability of biomarkers will help better define what could work for patients. For example, 1/3rd of patients with lupus do not express type 1 IFN. It is then useless to give them drugs targeting type 1 IFN... isn't it? The idea of precise medicine is to identify signatures in a patient's blood (IFN signature, neutrophils, a type of B cells.) that correlates with that patient's lupus activity, and then target the treatment to the cells that create that signature...

Studies using Artificial Intelligence and big data are also in progress to identify, in kidney tissue, those gene expressions differentiating LN patients to classify them to understand and even predict who will do better in different treatment options. Technology is moving, knowledge is growing, and a lot is happening to bring better treatments to patients, allowing a positive look at the future.

## **Annex 2 - Restoring Hope?**

*By Bernadette Van Leeuw, Psychologist, Chair of Association Lupus Erythémateux (Belgium)*

Bernadette started by challenging our convention title. Indeed, the definition of hope is often a mixture of passivity and simplistic optimism, such as the Wikipedia (French language site) defining it as "A disposition of the human spirit that consists in waiting for a good or better future". If restoring hope would just be waiting for the best to happen, it would be very close to denial or refusing to see a reality that would be unbearable. This is something we regularly see when people with lupus say that they are doing very well and refuse to take their treatment while their proteinuria scores are climbing dangerously. When hope is excessive, resulting in an unrealistic approach to the facts, it can obviously be negative. Restoring Hope is certainly not that!!!

Rather, Bernadette recommends defining hope as positive psychology (not positive thinking, like the Coué method) does, linking it with action in an inseparable manner. In the face of uncertainty, positive psychology assumes that there will be a favourable outcome and will push for action to facilitate this positive outcome. Hope is then a way of thinking but also a way to advance. Hope is the conviction that solutions are possible and that we are able to act. Hope is to think that every person, including ourselves, have an extraordinary potential for inner transformation and action. In front of the uncertainty of lupus, I will accept the situation, and then I will try to look at it in an active way, giving myself the right to consider a positive development to events and to act in that direction.

So, it is not necessary to spoil your life by rehashing the problems, but rather you can brighten it up by searching for positive sides or ways to improve things, taking responsibility for what we can change.

It is essential to have a fair balance between optimism and realism. Aaron Timothy Beck says that good mood is two-thirds positive thoughts for a third of negative... 66/33, that is slight optimism. Our negative thoughts are necessary because they protect us and allow us to remain realistic. Some use the term "Intelligent optimism", which derives its strength from the ability to imagine a favourable outcome to events and to give them more positive than negative reasons, but at the same time remaining lucid on the reality and the efforts to be provided.

Bernadette then explored the "objective" reasons that people with lupus often lose optimism, explaining that depression is substantially higher in people with lupus than the general population:

1. Symptoms of lupus are presented in a general way suggesting they are permanent: "90 to 95% of people with lupus suffer from muscles- or joint pain" permanently associates lupus and pain, rather than to clarify that pain outside of flare is, by definition, not lupus driven. This creates a nocebo effect: the very idea that one should have pain is a formidable mean to actually have pain!
2. Doctors (have to) insist on side effects of the treatments, and as a result, drugs are associated with their side effects rather than their benefits: Plaquenil means Retinopathy rather than reduction of flare and increase of survival. Cortisone is associated with Osteoporosis rather than "cut the symptoms". The patient then becomes sometimes more afraid of the treatment than of his illness.
3. Patients who are doing well do not speak on the internet, where negative rumours proliferate, increasing patient anxiety and slowly but surely putting them in despair.
4. The unpredictable side of lupus is presented as a fatality, leaving the patient powerless. In labs, rats with cancer, receiving electric shocks see their cancer evolve slower when they have a possibility to act (by pushing a button avoiding electric shocks) than those that cannot... The feeling of powerlessness is a driver of anxiety and despair. Nevertheless, the reality is that we are not powerless against lupus: just by adhering to treatment, we substantially reduce the risk of flares since not taking the treatment is today the largest single cause for flares!

Optimists live longer and healthier as demonstrated by countless studies. Thierry Janssen, a Belgian surgeon turned psychotherapist even claimed that "an optimistic attitude towards life is the most powerful and least costly drug that human beings have ever had at their disposal". Some of the effects of optimism are visible in biologic parameters (blood glucose, lipid profile), some in behaviours that have an impact on life expectancy (less smoking, ...) but those factors are not sufficient to explain why optimists live longer and healthier... Yet, Bernadette reminds us that we must not fall into the illusion that one can tame lupus just by our optimism and "inner forces", and that those failing have not been able to dominate lupus sufficiently! Not only is that ridiculous, but also adding guilt to the burden of disease, is not only counterproductive, but above all appallingly unfair.

So, the question is how to restore hope? There is no magic wand that works in every situation, no easy trick that can be taught in 15 minutes, but some things should better be avoided, and others better done...

There are three different "targets" to restoring hope: other individuals, ourselves and lupus groups.

#### Restoring an individual's hope:

Bernadette advised us to first listen to the person, with respect, empathy and authenticity.

Respect: No fear is stupid. It is important that people understand that you have respect for their beliefs and fears. This does not mean "approval", but listening with kindness, without interrupting, giving them time to express their secrets fears... Understanding their concerns is the first step to restoring hope!

Empathy, which means being at their side and trying to see the facts as they see them. Reformulating what they say, not just saying "I understand", but rather "if I understand, the worst thing for you is the wheelchair". Putting a clear name on things is important!

Authenticity: if you are not able to be fully present and authentic with the person, don't try to restore hope! You must believe in what you say, sentiments or facts. Or it will sound fake, and you will fail in restoring hope.

After the time to listen, it is important to bring clear facts and figures about lupus. Most of the time, people believe that their lupus is worse than it is in reality! It is also important to remind people that statistics can be misleading: The fact that 30 to 50% of people with lupus stop their professional occupation is very scary, but each person has a different risk for that, depending on the type of job, the education level, the severity of the disease, its duration, ....

There is no point in denying concerns with overly optimistic statements like "Don't be afraid, all will be soon OK." If believed, this encourages non-adherence to treatment ("Anyway, everything will be fine in the end") and brings huge disillusion later on. Rather, be realistic and express that lupus will bring difficulties, time wasted in medical follow ups, lots of medicines, but at the same time say that the likelihood is very high that he or she will be able to adapt and continue with a good life.

Restoring hope for people with lupus is to promote an "intelligent optimism", both an engine for driving projects and realism on the difficulties to overcome. When you repeat to patients that they have the means to live well with the disease and to succeed in their lives, you give them faith in themselves and in the future.

A big watch out is that some people are in such a mental condition that they simply cannot hope. This is unrelated to the severity of their disease. Even with a very mild lupus, some people are convinced that they will die in a couple of weeks. And sometimes, no logical or exact information, no support, will help them. You then need to accept that this is beyond what you can do, possibly advise them to get external help. We are not all-mighty and capable of 'restoring hope' to everyone. It is also important to protect ourselves by putting a limit on the time we dedicate to the "chronically desperate people" to avoid reaching the limit of our patience and throwing them away in an inappropriate way!

### Building our own intelligent optimism:

To be authentic, we must first "Restore our own hope" and be in a mindset dominated by "intelligent optimism" ourselves.

Just as we can ruin our health and life by rehashing our problems, we can strengthen it by looking for happy emotions. We have a rich potential that we must learn to use and develop by fighting against our tendency to self-deprecation, anxiety and pessimism. And this can be learned via methodically training. It is a journey to detect our own sources of satisfaction, grow them and build the life that fits us. It is important that we truly believe that there is a solution, even imperfect, to any problem. We have not chosen to have lupus, but we can choose our way of living with lupus and to look at lupus in another way, focusing on our possibilities, not on our limitations, becoming directors of what happens, not victims.

Bernadette suggests as an example of personal development exercises to wake up 30 minutes earlier, taking ownership for our day rather than being subjected to it. As you wake up, take the time to enjoy the silence, to consider yourself positively, to remind yourself of the "little victories" you can be proud of. Saying positive things about yourself on a regular basis increases your faith in the future. Then, consider the day ahead with a focus on pleasant moments, tasting in advance the feelings that will animate us at that time. The next moments should be dedicated to stretching exercises or yoga, to breathe calmly, to meditate, read a few pages of a good book, write in a diary, go jogging... The goal is to start the day with things that makes you feel good, but that you never take the time to do. Of course, it means you have to go to bed half an hour earlier the evening before, but it's worth it!

Another suggestion to build our intelligent optimism is the "visualization technique" to counter negative events: Visualize the worst possible outcome in a detailed way, and with a maximum of emotions, frame mentally the scene with a small dark blue frame and shout "I don't want that". Erase it and re-visualize in a positive way, with a large white frame and say "I want it to happen like this"; it helps to record our desires in a positive way deep inside ourselves and dispel anxiety. Even if things still go wrong (it is not magical!) the impact of this failure will be less.

Other suggestions from Bernadette:

- The "as X" game, thinking at how a person who represents optimism for you would react, and seeking to adopt the same attitudes (smile, right posture, straight shoulders, calm breathing...). If the psychological influences the physiological, the opposite is true also!
- Setting Smart (Specific, Measurable, Action Oriented, Realistic, Time Bound) goals to yourself. Every goal achieved, small or large, increases your self-confidence, personal esteem, and positive approach.
- Improving your physical condition (exercising regularly).
- Surrounding yourself daily with little things that give you a smile: photos, music, plants... meeting optimistic people and not people who pull you down. Optimism is contagious! Have fun: go out, laugh. Evacuate regrets and remorse.
- Expressing gratitude and joy, being more altruistic and generous: giving without expecting anything in return makes you happy.

### Building hope in your lupus group:

We cannot distribute hope like cookies, but we can create an environment that helps people cultivate hope. One of the ways to do this is to follow Timothy Beck's rule 2/3rd positive for 1/3rd negative. Ensure that your group's publications respects at least that proportion, creating the base for people to have hope.

Formally advise patients to consult only moderated groups if they want to interact on the internet. Faced with an adverse event, optimists will find an explanation limited to the event in question, pessimists will generalize: "everything goes wrong, everything will always go wrong, with me, everything can only go wrong... ". So, people in need for hope will easily consider that the worst things that they read on internet

will happen to them... One person dies of lupus, everybody panics. So, avoid connecting to anxiety generating groups!

Publish positive stories of people that have lupus, even very severe, but keep a positive attitude, like the "Reporters of Hope" award that highlights what is going well in the world, it is important to highlight these stories of patients who have managed to live in peace with the disease.

Ensure intelligent optimists moderate your lupus meetings.

Offer one to one time for people to express their negative feelings so that they do not pour it at length into a large group.

Provide complete and solid facts, easy to understand, and ideas for action for people to "beat the probabilities".

Remind people that non-adherence to treatment remains the number one cause for flares.

In closing, Bernadette urges us to find our own solutions to building hope, and to share them across countries so that the best ideas can be replicated across Europe.

