“EDUCATION TO EMPOWER”
LUPUS EUROPE CONVENTION 2019 REPORT

This year, we celebrated 30 years of LUPUS EUROPE (initially named ELEF) the official foundation documents being dated May 25, 1989. It was great to be all together in the UK to celebrate, and to build consensus and enthusiasm around our next steps. In a world where patient empowerment has become a critical feature of Health Care progress, the theme of LUPUS EUROPE’s 2019 annual convention, “education to empower”, brought our attention on the importance of getting quality information to our members in a way that empowers them to act with empowerment in their day-to-day care or in their engagement in the fight against lupus.

A total of 36 delegates attended the convention this year, coming from: Belgium (1); Denmark (3); Finland (2); France (4), Italy (5); Lithuania (2); the Netherlands (4); Poland (1); Portugal (2); Spain (1); Slovakia (1); Switzerland (1); and the UK (9).

[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.]

Friday, November 22, 2019

Pre-Convention Meetings

Our Patient Advisory Network met for a full day on the 22nd, working mostly on three significant projects. In the morning, we kicked off the work on “Patient care pathways”, a joint project with ERN ReCONNET aiming at better understanding the Patient side of the Care pathways by collecting as many short stories of patients as possible. The team worked with Dr Sara Talarico and Diana Marinello from the University of Pisa to define the process and the critical questions to be reflected in the survey to collect patient stories, and to understand the methodology of analysing narratives in a medical research context. The group also worked on defining the content of a “Clinical Trials” brochure, which we are co-designing with a partner. The object is to encourage people with lupus to consider participating in clinical trials and explain the next steps if they wish to do this. The brochure will not be trial specific, but will really focus on the general concepts that apply to any lupus clinical trials, in any country. In the afternoon, an extended group, also including non-PAN members, worked with another industry partner on “Lupus short- and long-term outcomes”. This topic is growing in importance. As we get better treatment, long term outcomes become more important over time. How do people with lupus assess short- vs. long-term? How is that included in treatment plans? What are their concerns or expectations? They had a very fruitful exchange that will be documented separately.

Friday was also the occasion for our Communication group (COMMs) to kick off the convention coverage and get organised with visuals, key messages and media channels to provide live coverage of the event (more on this below).

Saturday, November 23, 2019

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, and after sharing the full agenda of the convention, introduced Paul Howard, deputy CEO of LUPUS UK.

LUPUS UK is not only our host in this annual convention, but also a source of inspiration for all members with regards to "'education to empower". Its mission is "to empower people by providing information about lupus and offering support, so their voices are heard, and their condition diagnosed and managed effectively": a great summary of what we are set to work on during the convention. On behalf of LUPUS UK, Paul welcomed all participants and presented key activities of LUPUS UK, which 40 years ago, was the first group to introduce a Lupus National magazine for patients. Since then their education initiatives have grown substantially with a series of leaflets and booklets available in print and online, a highly successful website (500k visitors already this year), peer support groups managed by trained volunteers to help people living with lupus be more confident in managing their disease, and a web community of 25,000 persons, supported by HealthUnlocked. LUPUS UK is also a strong supporter of lupus research, soon reaching the bar of £10M cumulatively committed to research and to specialist lupus nurses, another great way to empower patients via education. Paul reminds all participants that all materials available on LUPUS UK's website are available for download, reuse and translation, only asking that the reference be clearly made to the source.

30 years of Lupus Research and Education

By Professor Graham Hughes

At the occasion of LUPUS EUROPE's 30 years, who better than Professor Graham Hughes to review those 30 years and what they brought in terms of progress and patient empowerment. Prof Hughes reminded us that it was in 1895 that William Osler first described the key features of lupus. It is however only in 1970 that the first specific test (Farr anti-DNA) was developed, thus allowing faster diagnosis of a disease that was still scarcely known and was treated with a massive 40 to 60mg of steroids per day! While many things have changed, early diagnosis remains a critical issue, as too many General Practitioners do not expect to ever see a patient with lupus. He recommends that GPs should suspect lupus when they see patients with hair loss, fatigue, rashes, recurrent or prolonged glandular fever, but who rarely catch a cold. After the initial problem of delayed diagnosis due to ignorance of the disease, the key issues in lupus are the ethnic and or geographic fluctuations in severity, the absence of specific treatments, the low awareness, and the low adherence to treatment. With regards to treatment, Hydroxychloroquine remains the key medicine, being safe at the correct doses, including during pregnancy. He feels confident that breakthroughs will continue to come from biologics, with so many being tested and with good reasons to be optimistic about the outcome. Prof. Hughes then urged us not to forget about Anti-Phospholipid Syndrome APS, which can be combined with lupus or a disease on its own, but remains substantially underdiagnosed. He suggests that Teenage migraine, recurrent miscarriages, memory loss, TIA and strokes are all pointers to “sticky blood” or Hughes Syndrome (today called APS). As APS substantially increases the risk for seizures (11x), it is not infrequent to see patients treated for epilepsy without much success, who then actually respond very well to APS treatment including Heparin. Thanks to early diagnosis and appropriate follow-up, the pregnancy success rate for women who are aPL positive (that is have **a**nti**P**hospho**L**ipid antibodies: used to diagnose APS and/or lupus) increased from 15% in 1985 to 95% in 2019. Yet, aPL detection is too often only considered after multiple miscarriages. Prof Hughes pragmatically suggested that any women who has had thrombosis, regular migraines and/or a family history of auto-immune disease, should automatically be tested for aPL after the first miscarriage. Prof Hughes then addressed the many factors that play a role in the incidence and severity of lupus: ethnicity, environment, adherence to treatment, economics, genetics… so much remains to be learned.

It was an excellent keynote speech, and we all thank Professor Hughes immensely for his years of generosity and engagement towards the lupus community.

LUPUS EUROPE Strategy#1 – People with lupus participate in, and benefit from, lupus research

Current and expected projects

1. INTEGRATE
2. THOMAS - Cardio vascular
3. 3TR
4. HcQ survey
5. ERN ADAPTE
6. Fair Net
7. Skin firm D
8. Lupus Advisory Board Firm E
9. Patient education
10. Patient care pathways
11. EMA advisory
12. Clinical trials brochures
13. LN mechanism - FOREUM
14. DORIS
15. LWL 2020

1. Firm A support
2. Firm B Support
3. Firm C support
4. Adherence brochure
5. Existing documentation
6. psychologic burden
7. Lupus clinic scan
8. E-learning inventory
9. GENIUS
10. Nutrition Guidelines
11. Patient Focused Medicine Development

LUPUS EUROPE was very involved in research last year. Thanks to the growth of the PAN, now counting 18 members, we have worked on 15 projects, and have another 11 in the pipeline, each with assigned PAN members . Some of the projects are short-term, others will last for years. Kirsi presented the list of those projects. Instead of covering each project, the team decided to present only four of the projects, as representative of the work we do.

The INTEGRATE project seeks to bridge the communication gap between patients and physicians and to develop a new strategy for the monitoring and treatment of SLE, by improving the integration of patient-reported data with the physician’s evaluation. LUPUS EUROPE contributed to two big workshops, one patient-only, the other combined with physicians, and is now engaged in determining conclusions and next steps.

The 3TR project is the first of its kind for LUPUS EUROPE as we are for the first-time part of a Pan-European consortium, funded by the EU. This in itself was a big challenge as we have to learn the very specific ways to work with the EU and develop all documentation for that purpose. Yet, once done, it will open the door to other interesting projects. 3TR aims at better understanding the mechanism of nonresponse to treatment, so as to develop new targeted therapies. Over the next seven years, it will examine massive amounts of data with hundreds of experts. LUPUS EUROPE’s role will be on the SLE-specific work group (other diseases are also covered by the project), and in the Ethics and Governance Team. This project will also give us an opportunity to learn from much bigger patient groups also engaged in 3TR, such as MS-Europe (Multiple Sclerosis) or EFA (Asthma and Allergies).

Wendy Zacouris then presented the key findings of our recent Hydroxychloroquine (HcQ) survey. As we obtained a stunning 2938 usable responses from 37 countries, we are not yet done with the full analysis, but results are promising. Wendy presented some of the key preliminary findings, which are under embargo… More to follow…
Finally, Angela presented the work started with ERN-ReCONNET to understand patient's care pathways by using a methodology narrative medicine, based on patients' stories. The plan is to mirror and build on the work already done for Systemic Sclerosis, using a limited number of questions and suggestions guiding the story written by the patients. Once collected, the stories will be analysed to determine similarities and differences, and seek to define, jointly between physicians and patients, an ideal care pathway for people with lupus.
Our plans for next year include further development of the PAN, in quantity of members (the goal is to reach 24), in depth of expertise (designing an endorsed course on lupus for patients) and in outreach (becoming European Medicines Agency eligible). We also want to contribute further with our own research, including a large "Living with lupus in 2020" (LWL2020) survey and a patient panel. Also, we will seek alternative ways to obtain contact with clinical trial participants so that we can reach out to them to understand their experience and share it with key players.

<u>Living with Lupus in 2020 - workshops</u>
Anne closed the Strategy 1 session by sending all participants to work on a simple topic: What should be the priority questions for our LWL 2020 survey? Participants split into four groups and came back with no less than 75 suggested questions. Several groups concluded that there were so many things we would like to know that most likely a survey in several waves would be required so as not to overwhelm participants with too many questions. All questions listed will be transmitted to the LWL2020 team for further work

<u>Exercise – launch of LUPUS EUROPE's Video Program</u>
By Jeanette Andersen – Chair – LUPUS EUROPE
The next session was likely the highlight of this convention: After a year of great effort, LUPUS EUROPE was proud to announce the launch of its Exercise Video program: five videos made by patients, for patients, showing how to concretely build up your exercise capacity step by step, from lying in bed to aerobic. Exercise is the only proven effective way to combat fatigue, but it is so difficult to start exercising when you feel tired and in pain, or have to stay in bed. The program, developed by Jeanette with an expert physiotherapist, and endorsed by the European reference Network ReCONNET got an incredible reception from all participants. It was released on the web so that it is available to all, free of charge. Furthermore, A4 pdf files are available to explain in detail the various exercises of the program 😊, and are available for translation. After a 10 minute exercise session guided by the video, and a big applause for completion of this wonderful project, attendees enjoyed a deserved lunch break!

Education vs. information

By Dr Meryem Maud Farhat, Internist at CHRU Lille, France

The word "information" may mean different things to patients and to doctors, but in both cases, information is just an organized set of data, which is a message about a given phenomenon or event. Einstein said that "Knowledge is acquired through experience, everything else is just information". Information has to be translated through analysis, decisions and experience to become knowledge and drive action. Dr Farhat explained that while information can be transmitted, the behaviourist model helps changing behaviour by learning behaviours when facing some specific situations, but the constructivist model goes further: it focuses on a deep understanding of concepts and available resources so that patients are able then to adapt their behaviour to new situations. Each individual's knowledge is not a standard set of information, but an individual set of information and beliefs that the individual constructs over time. The aim of patient education is to help the patient build an individual set of information, knowledge and experience that he or she can then use to improve their life with this disease. The process of patient education goes through four steps: 1. eevaluation of the patient's current knowledge; 2. creation of a jointly agreed personalized program (based on step 1), and often done by selecting the most appropriate modules of a general learning program; 3. Implementation of the chosen program using interactive presentations, roundtables, role-play, games, … i.e. learning methods where interaction and experience have a crucial role; and 4. evaluation of the acquired new skills and knowledge. A recent European survey, involving 601 SLE patients, concluded that only 20% had already participated in any formal Patient Education, but 93% of that 20% were happy that they had followed it. As the objective is to give patients ways to improve their quality of life, therapeutic education covers the many aspects of living with lupus, whether medical, social, behavioural, familial or communicative.

Parallel workshops on Education

All participants were invited to join one of the four workshops available:

1. Practising therapeutic education with Dr Farhat: This gave us the occasion to experience first-hand some therapeutic educational tools. One of the key take-aways is that, more than the answers to the quiz that form the basis of the training, it is the questioning within the teams, and the dialog with the expert that brings the most knowledge. A nice reminder that education is not just "knowing the answer", but rather integrating it in one's life and way of thinking. The Lupus Quizz game that was demonstrated is available for translation, but as we realised, it requires collaboration with a trained health professional to deliver its full benefit.

2. What are the key concrete needs in the area of patient education? In today's world, where we have different audiences, we need to use a variety of platforms (visuals, texts, workshops, leaflets, …) and each of them needs to be available for different levels of knowledge (basic, intermediate, advanced). The content has to be evidence-based, unbiased and certified, also identifying areas of uncertainty.

It should combine personal experience and scientific facts, addressing Euro-wide topics but bringing to light some national differences.

3. Another group on the same topic concluded that different levels of training (from very basic to expert) were a must, and that language had to be adapted to the level, so that complex topics could be understood by all. Topics should include best practices, and where specific behaviours or approaches are recommended, also explain the "why". The knowledge should come from, or at least be verified by, experts (doctors, nurses, …), and a quality certification "stamp" should be provided. Modern media should be used, but not to the point of eliminating face-to-face contacts. A suggestion was made that a "question box" be created on LUPUS EUROPE's website, and that these questions be answered by expert doctors. Finally, the information and education should be available on a continuous basis and free of charge.

4. What training/education is needed to improve patient engagement? The conclusion of the team is that it is really a matter of training all stakeholders, not just patients, but also academics, health authorities, researchers, … This education should be done both within the specific groups, but also in multidisciplinary teams, as the learning opportunity between the stakeholders themselves is also critical. While some of it can be "on the job", there has to be a formal basis to start from. For patients the EUPATI or Eurordis courses are great, but they already assume some level of knowledge. So it is key to start with the basics. For academics or researchers, starting from basics and involving patients in the training is also critical as there are many misconceptions that enter into play, and the only way to change the culture is by living it rather than just informing. How to deliver this education remains an open question, as the exercise is vast. Some should definitely be done at a level substantially above LUPUS EUROPE, through organisations such as EPF, EMA, … but LUPUS EUROPE certainly can and will contribute as we are able.

Open Q&A with Prof. David Isenberg

We closed the day with a Q&A session with Professor Isenberg. During this session, Professor Isenberg answered no less than 30 questions raised by the audience through the "pigeonhole" platform. As subjects touched virtually all domains of lupus, you will understand that it is impossible to provide here a summary of this incredibly dense session.

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 only highlights key outcomes as available for a broader audience.

After presentation of the Board and the Financial Report, the council adopted adjustments to the Constitution, creating Internal rules and a Code of Conduct. These two instruments are key steps to increasing our governance as we move towards becoming a larger organisation, with more people directly involved.

The council then thanked Helga Ovens, who is ending her mandate as Trustee, elected Marisa Costa (from Portugal) and Elfriede Wijsma (from The Netherlands), and renewed Kirsi Myllys' mandate as Trustee.

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

Strategic objective 2: "Member organizations are enthusiastic and empowered"

Kirsi and Annemarie provided their view on our key achievements to empower and energize our members.

Thanks to collaboration with members, we have achieved most of our goals in this strategic pillar: a great convention last year in Leuven; growing our address bank now to over 1000 interested persons; running two successful webinars to bridge from one convention to the next; supporting the emerging LUPUS EUROPE Youth group; and launching a new Kick Lupus Competition . The key miss remains attracting new members in countries where we are not yet present: while we have good leads, none materialised formally last year.

Next year, our key priorities in this area will be: (a) to bring new Eastern European members to the convention, (b) to organise yet another great convention, this time in Bratislava, and (c) to support capacity building projects in our national members. For LUPUS EUROPE to thrive, we need national groups to develop further, particularly the smallest ones. We would also like to see new faces at our conventions. The proposal was approved that next year we should offer fully covered participation, if one of the two national attendees is attending a convention for the first time, and if the member country properly relays LUPUS EUROPE's information to its national community throughout the year.

Poster Session:

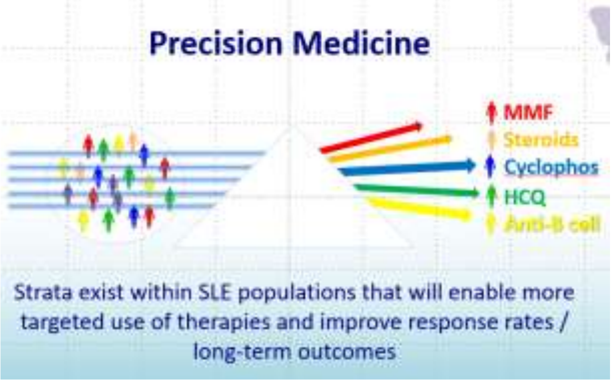
This year, it was suggested that participants present a poster on a topic related to Education. A dozen great posters were presented by their authors, sharing best practices or encouraging approaches from their respective countries.

Improving Outcomes in SLE: The Butterfly Effect

By Professor Ian Bruce, NIHR Manchester Biomedical Research Centre

Professor Bruce discussed a few selected key topics where additional therapeutic education would very much benefit people living with lupus. The first topic was the cardiovascular (CV) aspect of lupus, where he highlighted the bi-modal mortality pattern in SLE: for people with lupus, early mortality relates to the activity of SLE, but in a second phase, late mortality relates to coronary heart disease. In a Manchester study, he found that the rate of cardiovascular events for people with lupus was seven times higher than for the general population, but also that carotid plaque was substantially more frequent in people with lupus aged under 55 than for the same age general population. Research also shows that several risk factors play a more significant role for people with lupus, leading to accelerated atherosclerosis and hence premature cardiovascular events. As a result, he recommends fixing clear targets for cardiovascular risk factors (LDL cholesterol, blood pressure, diabetes mellitus, smoking and obesity) to proactively minimise CV event probabilities.

The second topic was long-term damage, using the SLICC Damage Index (SDI), which considers irreversible or permanent organ disfunction, occurring in one or more of 12 organ systems since the SLE diagnosis. An SDI above 2, five years after diagnosis, highly correlates with mortality over the next 7 years. A long-term cohort of 1722 persons also shows that damage begets damage, i.e. once patients get damage early, they tend to accumulate more damage. This is a critical reason why early diagnosis is important. Interestingly, the only two factors that show a negative correlation with worsening SDI are: being of Asian origin; and the use of antimalarial medication. Antimalarials, immunosuppressive drugs and targeted therapies enable one to control the disease and, combined with steroid sparing strategies, reduce damage and mortality.



Precision Medicine

Strata exist within SLE populations that will enable more targeted use of therapies and improve response rates / long-term outcomes

The last key topic addressed by Professor Bruce was therapeutic limitations. Since the 1990's, only four drugs have slightly enriched the available options for treating lupus: Tacrolimus, Mycophenolate Mofetil, Rituximab and Belimumab. However, contrary to RA, for example, which has seen 11 new licensed medications since 2000, only one has been licensed for lupus since Mepacrine in the late 50's. The good news is that several drugs are in the pipeline, with encouraging results, but each time, only for a limited number of patients. The silver bullet has not yet been found. The MASTERPLANS project, a large consortium, also including patients in the steering and work groups, seeks to identify new patient's stratification approaches that would predict which therapy will work for each patient. There is still much work underway in this project, but definitely an approach that should bring substantial benefits for people with lupus.

Kick Lupus Competition

By Kirsi Myllys, Treasurer LUPUS EUROPE.

The 2019 Kick Lupus team continued its mission to design an annual contest that inspires people living with lupus to kick their lupus a little further away every day, by focusing on what they can do to achieve this. This year, they asked people to send a short video on how they kick lupus…. We welcomed Andrealara Strepparava, from Italy, winner of the 2019 Kick Lupus Competition. Andrealara presented her story, or should we say what she remembered if it, as she suffered from a neurologic lupus that wiped out her memory for an extended period. Hence, she has no remembrance of the months she spent in the hospital as doctors tried to understand what she had. She was finally treated when they came to understand that it could be a form of lupus. Andrealara's complete speech is shown in attachment 1. It can be used to complement or explain her video available on LUPUS EUROPE's YouTube channel. (https://youtu.be/PDtPyDGDcv0)

It was a very emotional moment that ended with a standing ovation for Andrealara and her beautiful work.

Monday, November 26

Strategic objective 3: LUPUS EUROPE is heard and acting

By Anne Charlet, Vice-Chair LUPUS EUROPE and Helga Ovens, LUPUS EUROPE Trustee and Comms Leader

Anne explained how our overall landscape has evolved over the past year. Following our strategy to select partners to achieve our goals efficiently, we have actively engaged with specific organisations:

- EPF (European Patients' Forum - helping us to reach out political targets in Europe and to raise our profile with other key groups),
- Eurordis (opening the doors in the rare disease problematics and research), EUPATI (support for expert training),
- EULAR ("can't miss" in rheumatology, but also specific target for us is PARE),
- ERN ReCONNET - The European Reference Network for connective tissue diseases (working with best in Europe doctors and academics),
- Lupus academy and Pisa endorsed program (best in class for Doctor education),
- EFPIA (linking with the pharmaceutical industry, particularly via the Patients Think tank),
- IADPO – the international alliance for dermatology patient organisation (putting cutaneous lupus on their map)
- SLEuro, the European Lupus Society (involvement in congress organisation and reaching out to all lupologists)

These efforts have been quite successful so far as we find ourselves regularly invited to an advisory position for several of these groups, truly enabling us to leverage them to the benefit of our cause.

Another key achievement has been the creation of a focused communication group, the “COMMs”, which helped us issue four newsflashes, provided live coverage of EULAR, designed our exercise program leaflets, and actively covered this conference on social media.

For 2020, our priorities will be (a) to become “EMA recognised”, getting a voice in Health Technology Assessment, but also for protocol review and design, and other patient opinions in this critical organisation; (b) to increase our communication visibility, (c) to organise a face-to-face roundtable with industry, (d) have member news in each newsflash, and (e) to collect and publish at least 500 patient stories as part of the patient care pathways project.

Alder Hey Hospital

By Dr Eve Smith, Paediatric Rheumatologist and Mrs Sammy Ainsworth

TARGET LUPUS

- Structured approach to the management of JSLE:
  - Treatment target set
  - Frequent reviews to assess if target has been met
  - Escalation of Tx if target not reached at set time-points
- Already standard of care in rheumatoid arthritis

Liverpool has the great privilege of being home to Alder Hey Children’s Hospital, where a special clinic is dedicated to Children with Rheumatic conditions. Dr Eve Smith explained some of the key features of juvenile SLE (more severe and with a different disease presentation) vs. adult SLE (more renal, CNS and haematological involvement) and different challenges (maturity and coping mechanisms, adherence to treatment, risk-taking behaviour, questions about school and their future). Also, as the disease lasts longer, and has an impact during the development stage of the body, cumulative treatment side-effects and damage have to be even more carefully considered. The Alder Hey Hospital developed expertise in handling Juvenile SLE (JSLE) through a multidisciplinary approach and partnering directly with children, young patients and parents. They developed specific research such as, for example, a JSLE Cohort study that now includes more than 700 patients, the first ones having been enrolled in 2007. This large cohort study brings better understanding of childhood lupus and improved care.

Through the project “Target Lupus”, they worked on identifying relevant targets for young people with lupus, treatment strategies to achieve the target, relevant also for that age group, and from this, designed a Treat-to-Target study. This work is done together with their “Youth Participation and Advisory Group” whose role is to increase collaboration and input from young people with lupus. One of their other important areas of focus is supporting the transition from paediatrics to the adult care system, when the children under care turn 16. This is not an easy transition for many patients, so they have developed a process to make a gradual handover. This includes identifying doctors in the nearby hospitals that are ready to dedicate time and effort to support this transition, patient by patient, but also a follow-up by Alder Hey to make sure that the young adult is happy with the transition.

The youth group of Alder Hey is also at the origin of the WORD day (World yOung Rheumatic Diseases Day) initiative, on March 18th. The objective was to spread the word that Rheumatic diseases also affect children. The campaign had incredible results, with a 640,000 Facebook reach, but also very focused campaigns directed at paediatricians, post graduates, medical journals, … Sammy Ainsworth encourages us to all participate next year… and let them know what we are doing, so that they can amplify all actions around the world.

Sustainable Organisations

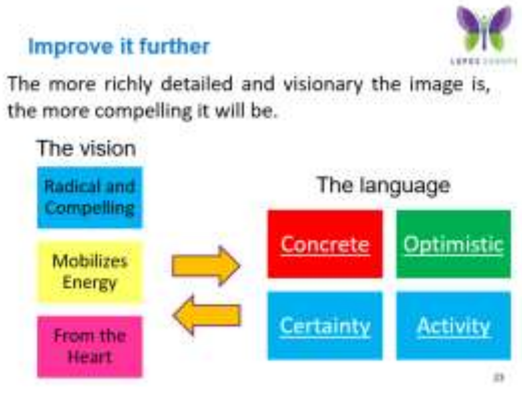
By Jeanette Andersen

Jeanette lead the group through an exercise she enjoyed during the EPF Leadership course that she attended over the last year. Working in pairs, participants exchanged thoughts on what makes patient organisations work, and what are obstacles in the way of reaching that goal. They then formed new pairs, sharing what they had just discussed and identifying possible solutions. Challenges can be many, like excess workload, lack of funds, lack of volunteers, … but when such obstacles are identified, then the next question to be raised is where YOU fit in, i.e. what you, as an individual, can do to make our organisations work better. Each participant took a few minutes to think about this question and write down the answer.

Vision… the Beginning of Leadership

By Alain Cornet

In the last session of the convention, Alain explained how leadership (which is the art of getting other people to want to do something that you are convinced should be done) is something that everyone can train to be better at. It requires developing skills in four key attributes: Envision (creating a description of the desired future); Engage (share this picture with individuals to be involved to identify solutions and move towards the end state); Energize (motivate people to achieve it); and Enable (equip people to succeed). We too often believe we have no visionary capacity, but we all can see issues… and can start to describe how things could be better. Alain asked participants to take one of the issues identified in the previous exercise and, instead of trying to describe possible solutions, describe how the organisation would be if the issue was resolved. To build a future, it does not matter if it is imperfect or fuzzy at the start, what matters is to write that ideal state, in the present tense and keep the mind on how great things will be when the problem is resolved, rather than how to resolve the problem. From there, we can start a process of "upgrading" this vision. A great vision has three qualities: it is radical and compelling; it mobilizes energy; and it comes from the heart. The first obstacle is that we too often limit ourselves by seeing only the problems rather than the full area of possibilities. To help resolve this, we need to use positive language. To put our thinking in a positive mindset, we can consider the issue, thinking "one thing that might be possible is…", and each time we say "but" replace it by "and". Participants then enrich their vision making it more radical, more positive, warmer, adding adjectives and descriptions that make the vision more enjoyable … The next step is to use "COCA" language. COCA stands for Concrete, Optimistic, expressing Certainty, and using words that suggest Activity. Using COCA words brings strength to the vision. Participants then, working in pairs, challenge the wording of their draft and replacing



Improve it further

The more richly detailed and visionary the image is, the more compelling it will be.

expressions by COCA words… To reach a great vision, that exercise has to be done multiple times, gradually enriching the image. The more richly detailed and visionary the image is, the more compelling it will be. To convey it to others, it does not matter that what we write is not yet in a nice and short format. This will be the next step (Engage), but as we build the description of our own vision, we gradually motivate ourselves to reach it, we grow our own energy, and obstacles start to fade in our own minds. We become Visionaries… we ARE visionaries!

Close of Convention

Jeanette Andersen closed the convention, thanking all participants for their attendance and wishing them a great year, before we see each other again, end November 2020, in Bratislava!

Kick Lupus 2019 Competition
Andrealara presenting her video

Hello everyone, my name is Andrealara, I come from Italy and I am twenty seven years old.
I decided to participate in the "Kick Lupus competition" to share with you my experience and what "Kick Lupus" means to me.
I lived with a neuropsychiatric Lupus for three years. I can tell you that I don't remember anything from that period, I know that I was treated for depression and nervous breakdown, and I also know that the specialists had given up on the "deep sea" which my head was.

I didn't recognize my friends anymore, I was afraid to go out of home and sometimes I was not even able to get out of bed. I locked myself in my room, I couldn't stand the light, I couldn't stand any noise.
I have no clear memories because ever since my Lupus started to walk with me he decided to take exactly that part of my brain where all my memories were kept.
Of course "good things" never come alone and one day my heart had a brief stumbling block, but serious enough to send me to the emergency room which, after, turned into a two month hospitalization. Two months of ''I don't know'' or ''I don't remember''.
So you might be wondering, what does a heart collapse have to do with a nervous breakdown? Well, it was thanks to this episode that the doctors found out that my heart and my right lung were more than twice bigger than the normal size.
Now, why should a nervous breakdown act this way? The answer is: it doesn't.
We finally understood that maybe I was not depressed, nor broken down, perhaps it was something else, but to understand all this, two spinal taps were necessary, and they were very painful, oh, no, wait, I don't remember!
The moral of the story is that when I was diagnosed Lupus, my whole life changed and also the life of all the people that are close to me: my parents, relatives, friends . . but not for the worse.
I wish to bring a positive message as I did before telling my story in "Storie di Lupus", the book was published in 2018 by Lupus Italy (Gruppo LES Italia), ten stories of people with Lupus and mine is one of them.
I like to define myself 'an artist', an artist is not one who paints or sculpts but it's one who has the ideas, that's why I like to define myself 'an artist'.
Actually I did study sculpture but my Lupus made me understand that such a heavy work will never be part of my future. But there are many different kinds of art and … I'll never give up!
When I participated to the "Lupus pic nic" and I asked my friends if I could make some recordings for the "Kick Lupus 2019 Competition", I could never ever imagine I would be the winner and to be here today and speak to you.
I am a creàtive person, I like to experiment and observe how people react to my initiatives. I prepared some purple bands (to wear) and a white cloth on the ground, and asked my adventure mates to do whatever they wanted to do, we had some good music by 'Pizzicarelli Varese Group', they have been special Lupus supporters for a long time, and we enjoyed a great day, singing, dancing and laughing altogether.

In this video we can see a group of people just making fun of Lupus, wearing purple shirts and bands, and when they dance they know that tomorrow they will probably suffer from terrible pain, perhaps won't be able to get out of bed, or won't even want to leave their home, but in that very moment they danced, they laughed, they had fun, because Lupus is also this.

Lupus makes you understand which are the moments you can be happy and makes you enjoy these moments more than anyone else could ever do, because nobody can understand what it means to renounce something because your body can't make it, and this is why we "fully live all our experiences".

Lupus is not my enemy, it's not something I hate, it is part of me, and I can't hate a part of me, because I like and love myself the way I am.

It's not necessary to be in good physical shape or to be an athlete to give Lupus a kick.

All I need is a special day, like the one you can see in the video, with my family and my friends, under the trees' shadow, laughing, singing, dancing, or at least trying to do it, and, above all, supporting each other.

Now, I'd like to end with a quotation from my story published in the book "Storie di Lupus":

When you are affected by this "invisible illness", very few people understand how you really feel because you look fine and perhaps they think you are just tired.

But the ones who are close to me, they fully understand me and need no explanation because they know I'm not feeling good and that I'm not pretending to be ill. Sometimes they understand I'm sick before I realize it myself.

At this point I am somewhat proud of my Lupus, it is part of me and I accept it. One day, when 'he' will wake up again, and I know that this could happen, I will have by my side special friends that will help and support me. Thanks to them the "Wolf" will be put back to sleep.

Thank you
Andrealara