



“PAIN, FATIGUE AND STRESS”
LUPUS EUROPE Convention 2017

LUPUS EUROPE’s 2017 convention took place in Milano, Italy and was centered on the theme of “Pain, Fatigue and Stress”. Pain, fatigue and stress are commonly reported as a significant burden on Quality of Life of people living with lupus, even when the disease is in a remission stage. Understanding the mechanisms that drive these symptoms, from a Biologic point of view, but also their Psychologic or Cognitive components are all critical to effectively help people with lupus enjoy a better life.



Our convention took place at Da Vinci Hotel Milano, where participants gathered on November 15th for a Welcome dinner before the start of the Program on November 16th. We are very grateful to Augusta Canzona, Daniela Rava and the Italian Team, for the preparation and the hosting of such a great event in a perfect place!

[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 will be available shortly in the member section of our website.]

Thursday, November 16, 2017

Opening session – Welcome

Kirsten Lerstrøm (Chair of LUPUS EUROPE) and Augusta Canzona (Chair of LUPUS ITALY) welcomed all participants in the “purple palace of Milano”, Hotel Da Vinci. They highlighted that the convention would also be followed on Facebook and Twitter. Lupus Italy has very close relations with the Doctors, which they



accompany from the time of their study till operation in Lupus Clinics, and we were very fortunate to benefit from their attendance in this convention. Kirsten welcomed the 4 representatives of Industry (Neovacs, Boehringer, Merck and GSK) that joined us Thursday and Friday tomorrow lunch time. She expressed the wish that we all bring some learning to share with our respective groups back home. Last year, we polled participants at the convention about the theme they would like to hear about next, and Pain, Fatigue and Stress came in loud. This theme was also a key finding of LUPUS EUROPE’s first ever survey in 2008 survey.

Why are pain, Fatigue and Stress (PF&S) so important, and why is it so little talked in consultations?

Kirsten then introduced the agenda for the convention, a mix of lectures from our Italian Doctors, sharing of experience, interactive presentations, workshops and skill building, punctuated by “move” sessions that will be led by Jeanette.

Pain, Fatigue and Stress

By Chiara Tani, Rheumatologist at Pisa Clinic in Marta Mosca's team.

Dr Tani opened the discussion stressing that PFS is a very important topic for patients, but also for Doctors that face the questions of their patients every day.



Fatigue is critical because it affects 50-90% of patients, being a major symptom for 53-80% of patients and half the people are limited by these, making it a frequent cause of absenteeism at work, impacting quality of life, work ability and productivity. Participants input on the various causes of fatigue: inflammation, pain, sleep quality, cortisone, cognitive impairment, stress, comorbidities, lack of social support, mental load of treatment management, vitamin D deficiency. Fatigue is multidimensional. When consulted about fatigue, the first step for the doctor is check if the fatigue shows a disease activity change, but

in most of the cases, it will be something else, like muscle weakness, anemia, depression, anxiety, lack of physical inactivity, Fibromyalgia (a frequent lupus co-morbidity), so there are many possible reasons for fatigue, and finding the cause is important to treat it.

A study showed that «fatigue» is addressed in 62% of the first visits, but only 6% of the consultation time addresses fatigue: typically at the request of patients due to the functional limitations that it causes. To effectively communicate, Dr Tani recommends to observe it (when, what limitations, how it is triggered), quantifying symptoms over time or objectivize it via questionnaires (Pisa uses Facit's simple 10 questions) or diary.

You then should «Listen» to your body, understanding your «limitations», and spread your work over the day, for example. Aerobic physical activity practiced regularly is a very helpful tool to fight fatigue. You can also plan your activities, taking some breaks and planning your activities and daily tasks. Stop smoking.

Also, realise that you are not alone: Other patients and Patient groups can give you suggestions on how to improve. Sleep quality is critical, so you must install a stricter sleep hygiene (regular hour to go to sleep, no laptop, no heavy meal in the evening...) and possibly seek medical or psychologic support.

Participants shared their own tricks: Wendy got a puppy when she was feeling really bad, and that forced her to walk which improved her fatigue. Dr Tani highlighted that 40 minutes of good walk a day is perfect! Simone shared that those members of the German Group that have identified being involved in a hobby they love, experience fatigue improvement.



Pain in SLE

Pain DUE to SLE	Pain associated with SLE
Inflammatory joint pain (arthritis)	Non inflammatory joint pain (osteoarthritis)
Peri-articular pain (tendons and bursae)	Fibromyalgia
Serositic pain (pericarditis, pleuritis)	Fragility fractures (osteoporosis)
Neuropathic pain (neuralgia)	Avascular necrosis
Lupus headache	
Painful skin lesions	

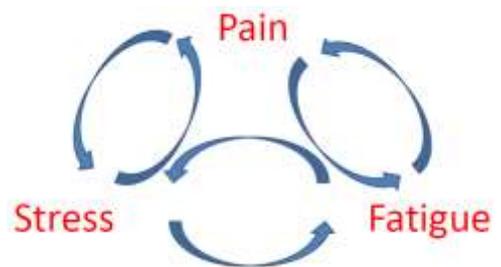
How to distinguish?????

Pain is also multifaceted, some due to SLE like joint pain, painful skin lesions, neuralgia, ... and some that is associated but not directly due to lupus like osteoarthritis, migraine, fragility fractures. To help deal with pain, it is important again to help your doctor understand it. This can be done by describing your symptoms (where, when, intensity, triggering factors, ...) potentially keeping a diary. It is then important that you follow the doctor's prescriptions (pharma or non-pharma) and then report on how it worked. Several pain scales exist, but they remain a very

subjective and are mostly meaningful as a trend – how is it evolving versus previous time?

Fibromyalgia is a very frequent co-morbidity of SLE, being present in up to 30% of people with lupus, and we have to recognize if the pain is due to SLE or Fibromyalgia. The fatigue both physical and mental in SLE is significantly influenced by the concomitant presence of Fibromyalgia.

On the subject of stress, participants experience is that the diagnosis was a cause of stress, the fear of “what’s next” with my lupus, but also that everything can be attributed to lupus. Also, the worry that you have to give up many things, won’t be able to handle everything, the inability to meet deadlines or requirements, fear of being a burden to others, Internet and Facebook... are key causes of stress. Lupus Germany studied stress few years ago and found that people with lupus manage stress differently than other people. This would be a great subject to further study. The causes of stress are very different by individual! Stress impacts people with lupus in a similar way than any other people, but on top, stress can be associated with the first appearance of their lupus and with a flare-up of their existing disease.



Finally, Dr Tani concluded that Pain, Fatigue and Stress feed each other, and it is very important to work on these, individually to tackle it, with the doctors to work on it together, and to research so we keep growing our knowledge.

Kicking lupus - MOVE

By Jeanette Andersen, Secretary of LUPUS EUROPE

After a Coffee Break, Jeanette introduced a series of exercises that have been designed by LUPUS EUROPE and a Physiotherapist starting from the insight of “Kick Lupus”. They are designed so that everyone can do



some, even those that are in bed. We need to kick lupus, and that starts with small things, small movements when you can’t do more, and gradually doing a little more every day. In this convention, we experienced the 5 “levels” of exercise in an accelerated way, starting with a session that people can do in bed, when they have very limited mobility... to then go the next day on exercises you do while sitting, then standing, then “jumping” on the last day.

LUPUS EUROPE’s plan next year is to develop short videos that will show how to do these exercises. Studies show exercise to be the only effective “treatment” for lupus fatigue.

Patient-Doctor Communication gap

By Chiara Tani, Rheumatologist at Pisa Clinic in Marta Mosca’s team.

Dr Tani engaged in a dialog with participants on the communication gap and asked what participants expect from their doctor. In some countries, just having an appointment, preferably with the right doctor, at the right time appears a real challenge. Patients want to be listened to, to be taken seriously. They seek a multidisciplinary approach while being followed by the same doctor. Time is a big constraint, and doctors do have time allotments from social security in several countries. It is also suggested that doctors could direct their patient to patient support groups: When a doctor recommends it, it helps a lot!



Effective doctor-patient communication can be a source of motivation, an incentive to follow treatment, a reassurance that you are well handled and leads to better diagnosis and tailored treatment plan. It even has positive impacts on the cost of treatment



because it avoids prescribing ineffective drugs and improves adherence to treatment. A study published in 2000 on Cancer showed that Patients' agreement with the doctor about the nature of the treatment and the need for follow-up is strongly associated with better outcomes: increased ability to tolerate pain, better recovery from illness, decrease in length of hospital stay, decreased tumor growth, better daily functioning and better mental health. There is no reason similar findings would not apply in Lupus.

Yet, Patient – doctor communication is not where it should be, Studies have demonstrated patient discontent even when many doctors considered the communication adequate or even excellent. As an example, 75% of the orthopedic surgeons surveyed believed that they communicated satisfactorily with their patients, but only 21% of the patients reported satisfactory communication with their doctors!

Considering obstacles to communication, participants mentioned the patient's high consideration for doctors (creating a fear or concern not to lose their time), the mood of the day, shyness, discouragement... The reality is that there are both Patients and Doctor shortfalls. Doctors for example are not trained in communication, so it will depend on each personality. Physical settings will also intervene (privacy of the room, seating arrangements, presence of the nurse, stress when an appointment is delayed, disturbances impacting the ability to communicate).



Another factor is that what Doctors and patients expect from the discussion typically differ. This is because the evaluation of disease activity and damage accrual are the key points in the assessment of SLE patients in routine clinical practice, but they are poorly associated with measures of quality of life, which is what patients consider. Even in the assessment of disease activity, patients and doctors will focus on different measures: patients tend to focus on self-perceived functions (fatigue, insomnia, pain, ...), physicians tend to be more concerned with clinical signs and laboratory results. A study identified that Patients' predominant concerns in consultation centered on function and fatigue, whereas physicians' concerns focused on SLE-related organ complications. The highest ranked patient concerns (fatigue, pain and feeling worn out) are routinely assessed by only 48%, 43% and 9% of physicians, respectively.

To remediate the communication gap, Dr Tani explains that we need to evolve the doctor-Patient communication model into a mutual participation model, Transforming patients from passive recipients of

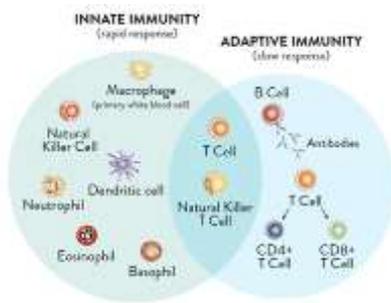
MODEL	PHYSICIAN'S ROLE	PATEINT'S ROLE	CINICAL APPLICATION OF MOEL	PROTOTYPE OF MODEL
Activity-passivity	Does something to patient	Recipient (unable to respond)	Anesthesia ,acute trauma, coma ,etc.	Parent-infant
Guidance-cooperation	Tells patient what to do.	Cooperator (obeys)	Acute infectious processes, etc.	Parent-child.
Mutual participation	Helps patient to help himself.	Participant in "partnership"	Most chronic illnesses, psycho-analysis, etc.	Adult-adult

information or instructions, into active participants in the management of their disease. This is Patient empowerment: (1) Emphasis is on the patient talking and the physician listening and understanding the needs of the patient; (2) the physician giving opinion and information and (3) the patient making choices together with the physician, which implies that the patient is asking and the physician answering...

In the most recent recommendations for rheumatic diseases released by EULAR, one of the overarching principles is that treatment should be based on a shared-decision process between the patient and the physician. This is an area where Patient Organisations can play a big role, as we can help our members shift their approaches and adopt this communication model.

Basic Science on Pain-Fatigue and Stress

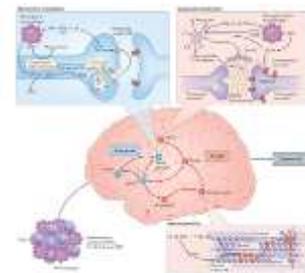
By Sara Badreh, LUPUS EUROPE trustee in charge of Research, and PhD student in translational medicine



Sara led us through basics of immunology. The innate immune system is what we are born with; the adaptive immunity is what we develop during our lifetime as we face pathogens or others in our environment. Amongst those, dendritic cells (also called APC) will take the threatening cells and present the intruders to T-cells to seek help to destroy it. The CD8 T-Cells are the James bond of the body: they have right to kill, they just go and kill the target. The CD4 T-Cells are stronger, but will only move if you really insist that they should be working. That is good because they are so strong that they could do serious damage if they

were let free to do whatever they want. Within CD4 T-Cells, there are various subtypes with different roles. To communicate between themselves, cells use “Inf” and “IL” “codewords”. The process of mobilizing T-cells does take a bit of time, as cells need to talk to each other, trigger them to react, and possibly there is a long chain of reactions that is required to create the end results. This is why some treatments take time.

If we consider stress, whether Mental or physical, it activates mechanisms that trigger our immune system to react. For example, the signal can deactivate serotonin production, which then creates a chain reaction which can move into loop reactions. In pain, the inflammatory code words are triggering reaction in tissue that cause them to swell up, that creates oedema, that trigger pain, that ... and if the immune system is not properly regulated, the reaction goes in chain and overreacts. In fatigue, a number of interferon



induce tiredness. In most people, that is not a bad thing, because the immune system works better when you sleep, so one of the reactions of the immune system can be to make you tired, so that you rest, so that you recover faster. But if that is not properly regulated, you imagine (or experience) the effects.

So, the issue of SLE is one of a vicious circle, where our immune system is so active that it creates chains of reactions. Those chains result in bigger Pain, fatigue and stress.



LUPUS EUROPE's New Strategic plan

By Alain Cornet, Secretariat – LUPUS EUROPE



Starting with the 2016 Wurzburg convention, LUPUS EUROPE's board of trustees has worked on an updated set of strategic goals to drive our priorities over the next 5 years. In a dialogue with Academics, researchers, other patient organisations, Industry and our members, we have identified how we could build further on the 2013-2017 Strategic plan to take our results to the next level. Our vision of “A fulfilling life for all people with lupus in Europe until we have reached a world without lupus” remains unchanged, and the pillars of our action, (1) Research that benefits people living with lupus, (2) Empowering members, and (3) Being heard and acting also remain, but our past successes will allow us to reach further in each of these areas.

Using the temple visual, Alain showed how these pillars support our vision, and adds the dimension of sustainability, which will be a key element of our action, to ensure the long-term stability of the full building. He then went on highlighting our key strategic objectives for each pillar and the specific deliverables that we are considering for the next 5 years.



We will not cover in this report the full details of the plan presented, which are available on LUPUS EUROPE's website. Rather, we will focus on a few most significant changes introduced by the new plan:

In the area of research, we will create a Patient Expert Group, 7 to 10 trained and energised Expert Patients, appointed to act as a liaison and resource to scientific projects and Clinical Trials related to lupus. This group will operate as a network, connected to the broader community of patients interested in Research and to our members. We will also intensify our own research with annual rather than bi-annual patient panels – the next one being on youth, and with participation or initiation of at least one quantitative survey every year.



To empower our members, we will create new, web-based collaboration structures, as well as working groups that will focus on specific topics throughout the year. Obviously, conventions will remain high priority.

In terms of increasing our external impact, we will define and deploy priority message tracks and toolkits to ensure these are effectively relayed, and amplify our presence at key events where we can make a difference, as well as taking an active role in the European Reference Networks where we have recently been appointed as the voice of Lupus patients.



Our Strategic plan also includes a significant focus on ensuring sustainability. This is both in terms of Financial and non-financial resources, ensuring sustainable funding and Increased human resources in support of our activities. The constitution changes to create a General Secretary position to support the board is a first step in that direction. Sustainability will also mean focusing on LUPUS and on EUROPE.

Alain concluded saying that, as we worked through our strategic plan, the need to better express the evolution of LUPUS EUROPE's personality emerged. Our logo, the butterfly 'surrounded' by 2 hands expressed the care we have for all people with lupus very well, but felt overly protective; possibly constraining and limiting. A fulfilling life means empowering patients, helping them to become actors and leaders of their lives, standing up and stretching their wings. He then unveiled the new logo that Patrick from setfire.to designed after working with the board on what we stand for, our vision and goals. The logo was strongly endorsed by the participants and adopted.

Participants then moved to workshops on key topics covered by the strategic plan, leading to the following outcomes:

Patient Expert Group (PEG)

The team summarized their work as follows: The PEG should be a team of up to 10 patients with diverse expertise, appointed by LUPUS EUROPE, but highly connected to the broader community. EUPATI, PRP or other education providing a solid knowledge of lupus, its mechanisms and impact on life, as well as of research in the medical area will be welcome. Being involved in the PEG should be based on both interest



and background, as well as experience and training in the field. This is not just general training, but also lupus specific knowledge. Through Web meetings and 1 or 2 face to face meetings each year, the group should bring together Expert Patients to share thoughts on issues raised, design common best approaches or “LUPUS EUROPE point of views”, share new developments, coordinate the requests for support to ensure suitable volunteer(s) assignment and prompt/consistent answers. With this in place, we should get an active dialog with researchers (academic and industry) to

promote patient views and develop better approaches. It is important that participants are involved in the community and can bounce ideas to each other.

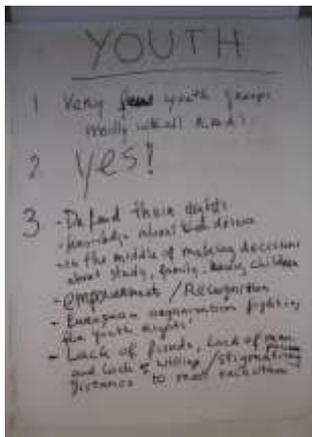
Kick Lupus

The group considered how the Kick Lupus initiative can help fight pain, fatigue and stress. They found out that a critical element is to have something that you are passionate for and that will get you out of bed regardless of how you feel. This can be any activity or hobby, learning things, ... The group then considered how we can Kick Lupus in other areas. Clearly, each time we encourage ourselves or others, and get active in doing something against lupus, we Kick Lupus. We can help each other, as member organisations, to be more dynamic in that respect, and to stimulate each other so that we find more energy. The team concluded that for the next year, all should relay the initiatives done in each country... this can help us move and kick lupus. The request is made that each group mentions what they do to Kirsi@lupus-europe.org



Youth

The group highlighted that most national groups do not have a lupus youth group, and where they exist, it is rather Rheuma-broad than lupus specific. Young lupus patients don't recognize themselves in these rheuma youth groups, nor do they in our national groups that mostly group “older people”. All agree that we need a Lupus Youth Group. Young people have other needs (studies, work, relationships) and aspirations (having children, ...) that need to be better represented in our activities and priorities. They also have difficulties finding peers as they are few. The national level is too small to do something meaningful in that respect, so we need to truly move to the European Scale.



In most countries, lack of resources is a roadblock to creation of a youth group, at the same time there is limited willingness of young people to join because of the stigma they fear. Also, the geographic distance is an obstacle to meet regularly. A European youth group would help them exchange points of view, spread awareness on how to have a good life with lupus (life expectancy for

youth with lupus now is almost normal, no need to scare them with old horror stories), and share best practices. The group could also raise questions and request for support to LUPUS EUROPE. The team identified 18-35 as the target range which is what the Rheuma groups do. Italy works with 16-26. There is a LUPUS EUROPE Facebook youth group, so please get your people in it!

A big question is how we can remove the stigma of lupus. This is a critical barrier to work on. We should see if we could get a famous person part of our youth Facebook group. Next patient panel will be about Youth, so participants were invited to think at Young people (18 to 26/28) that could join this unique experience.

Communication

The group worked on a reverse logic: Rather than ask “What should we do to improve communication?”, they turned the question on its head and asked, “What, in terms of communication errors, would push you to DISENGAGE from an organisation?” Participants then listed what would push them to disengage from any organisation - not specifically Lupus Europe. Next, based on all responses collected on a “spider” diagram, they asked themselves, “Are we, at Lupus Europe, guilty of doing this?”.



- On the list of things people said we are NOT guilty of included putting people in front of a “fait accompli”, being politically led or serving personal interests, lacking respect for other groups, or publishing unreliable info.
- Things that we need to pay attention to included using jargon, acronyms, too complex language; ensuring that all feel valued; be aware of language barriers, excessive info/long texts (we have improved a great deal on this).
- Things we ARE (at time of workshop) guilty of include lacking context (forgetting to introduce a person/idea), poor layout/visual identity; lack of FAQs or easily searchable info; poorly timed or out of date information.

The input of this group will be carefully considered as we finalise our new web design and content.

Partners against Lupus

Overall, our plan was very well received by our sponsors. They suggested its communication could be improved by explaining the background and the issues we need to tackle in order to reach our vision, something we take as granted, but is not for others. This could be accomplished through message tracks explaining why we exist.



“Heard and Acting” is fundamental: If we need to speak with politicians, it’s important to be very clear about what we need and want. It was also felt that we could communicate more about our rules of engagement in our work with the pharmaceutical industry. We use EFPIA, but many of our members do not know those.

Our partners were very pleased to see Research as a key part of our strategic plan. Patient education on the Clinical trials process is very important, and the industry could help. All participants expressed strong interest in continuing the conversation with LUPUS EUROPE and with the other

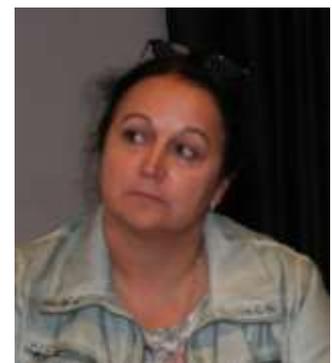
sponsor representatives. Some topics can be discussed together, and the sponsors can combine efforts with Lupus Europe.

The team work concluded with two suggestions: (a) hold an education and dialog program with (some) convention participants the day before the convention, and (b) Consider the possibility to seek sponsorship of members to attend Eular in exchange for a Sharing session with pharma.

Country Sharing - Germany

By Simone Pretis Vice Chair Lupus Germany

Lupus Germany really enjoyed celebrating its 30 Years with LUPUS EUROPE in Wurzburg last year. The last 12 months have been very challenging for the group, with a 3% decline in membership. This is partly because internet



Page 8 of 24

replaced physical local contacts. The next year will equally be challenging as Chair Borgi, Vice-Chair Simone and 2nd Secretary Ute will retire by April 2018. Identifying replacement has been difficult as time and health pressures have put a strain on resources. New support and distribution of tasks will be needed. On the positive side, the Lupus long-term study (LuLa) will be continued (it runs already 15 years), and the 8th Lupus Day of Science has been a big success with two days of intense conference for lupologists. Also, a Dental study revealed surprising data, showing the need to work on better dental care for lupus patients. The group is now working on admission for sunscreen... So, despite the organization issues, the group is keeping active. Well done!

The first day of hard work is closed with an open bar brainstorming session...

Friday, November 17, 2017

Kirsi Myllys, Treasurer LUPUS EUROPE opens the day with a presentation of today's program, leading us to country sharing by Greece

Country Sharing By Greece

By Anna Karliampa & Katerina Darika, Greek Delegates



People with Lupus can face serious problems throughout their work life because the disease is so unknown. Pain, fatigue and doctor visits are the most common daily problems people with lupus face, but lack of acknowledgement is a key underlying issue. Greece initiated a project to determine how people with RMDs can address and communicate their disease to their work environment, making adjustments to ease their work so that they feel happier and more fulfilled while working when having a serious condition. Throughout this project, participants attended seminars that covered Labor law, case studies, how they cope

with your working environment, Changing career, Role play and a personal assessment and professional plan.

Events, this past year

Session led by Kirsi Myllys, Treasurer LUPUS EUROPE with interventions from all Trustees and Co-Opts

Kirsi showed us how active we have been over the past years with a rolling list of the work delivered since last convention. Every single month, LUPUS EUROPE delegates have attended events, engaged in Research, made presentations or run workshops. A wealth of activities that was then explained by the team.



Davide Mazzoni, Co-Opt LUPUS EUROPE showed us few examples of his involvement



in Research. He is member of the REFRACT project, funded through FOREUM. Refract is targeting Refractory lupus nephritis, and seeks to understand the efficacy of Rituximab. He also collaborated to the ELM in Venice where he made an oral presentation on "Social support and quality of life in SLE". Another LUPUS EUROPE delegate, Marina Falanga presented on "patients' unmet needs and improving care system" based on the Italian survey on the subject, and 3 other patients presented posters – a great success! Finally, as another example of our research engagement, Davide presented the publication he did in in 'Musculoskeletal Care', based on the 2nd patient panel. This publication has since been the base for 1 oral presentation and 2

poster sessions in different congresses on Patient engagement research.



Sara Badreh, LUPUS EUROPE trustee then highlighted some other research related activities. The EULAR Patient Research Partner (PRP) network is a great way to support research, and 7 lupus people participated to the meeting. Sara participated to a Think Tank in Washington DC, an event seeking feedback on Future medicine design for Lupus. Tables were arranged with Doctors, patients and scientists, and each person had to think at how to tackle challenges like impacting policy makers... What was interesting is that Doctors had to take for example Patient's role, so they had to put themselves in the skin of a lupus patient. Sara also participated to Lupus Academy, where young lupologists meet very experienced doctors. For the first time, we represented patients, and it was interesting to see how our concerns and Young doctor's concerns are so similar.

This was an eye opener on how much we need to better communicate. This topic was also discussed last week with the people designing CME programs. In a similar vein, Sara attended the 8th EULAR endorsed course on SLE. The target there is Rheumatologists that are thinking at specializing in Lupus. Sara provided patient views, and handed over our letter to the doctors, written at the end of patient panel 1.

Jeanette Andersen, Secretary of LUPUS EUROPE, shared her experience with EULAR, where she has been active for many years now. This year, she supported the "Don't delay, Connect today" efforts, a EULAR Campaign aims to raise awareness of the importance of early diagnosis in preventing further damage to those living with RMDs, and to encourage timely access to evidence-based treatment. Interestingly, EULAR regularly has funds available for awareness arising that members should consider applying for! Jeanette also participated to the EULAR Conference on reducing the burden of chronic diseases in the workplace for people with RMDs, an event focused on identifying and discussing issues related to the working environment and how to move forwards. Finally, Jeanette was our delegate to the PARE Youth meeting held last October in Belgium (Chaired by "our" Petra Balazova). This was a stimulating experience, but it also highlighted the work remaining to have youth groups in each country. EULAR is a huge organization, its last congress in Madrid gathered 14,300 people, doctors, scientists... and patient representatives. LUPUS EUROPE and its attending members shared the work to attend a maximum number of relevant sessions. Several learnings were shared in our June Newsflash. Jeanette insisted on the topic of patients' role to help each other. When your doctor tells you to quit smoking or exercise, it is much less followed than when a fellow patient tells you how much quitting smoking or exercising helped her feel so much better.



Kirsten Lerstrøm, Chair Lupus Europe, showed how we reached out beyond EULAR. She attended ACR, where she had to register as HCP, as there is no patient registration category. This was the occasion to connect with LFA and attend a project meeting on EULAR/ACR reclassification of SLE. This year also was an ICL year, with only few patients present due to the travel burden of going to Australia, yet discussions were good, identifying the need for more consistent communication about lupus. This is something where the World Lupus federation (WLF) should, with our support, play a growing role. In WLF, we are active in various work groups. The recommendations under preparation include designing tools for groups to support operation (organization, volunteer management, fundraising); how to set up, run and use survey and results; and possibly setting up a mentor program. Work is also on-going on the subject of synergies, for example on WLD, branding (logo, color, events), and establishing a central repository of validated information.



Katharine Wheeler, Vice-Chair of LUPUS EUROPE, then explained our very active engagement with EPF (the European Patient Forum). As LUPUS EUROPE, we do not have yet the scale to access EU parliament, but through EPF, we can. Katharine will talk at an EU session on the Roadmap to Achieving Universal Health Coverage for all by 2030! She engaged on this topic through the EPF Access working group that worked on this a whole year. With EPF, Katharine also participated to PRO-STEP's conference, a pilot project on promoting self-management in chronic diseases. Unfortunately, EPF is under pressure as EU is reducing their funding for Health Care, which includes Patient groups support.

Annemarie Sluijmers, from NVLE, helped us in our outreach project. She collaborated to the EPF work group on Safety. Last April, EPF put a first paper mapping the key safety risks, knowledge, attitudes and skill of patient and/or carers. This led to the development of a proposal on building key competences for patients and families in patients safety. Annemarie also represented LUPUS EUROPE for our first attendance to International Alliance of Dermatologic Patient Organisations (IADPO). This was a meeting of delegates of Skin Patient Organisations, globally. They are launching the GRIDD project (Global Research on the Impact of Dermatological Diseases), a Patient-initiated research project to improve access to care and treatment of patients with dermatological diseases.



Anne Charlet, Vice-Chair LUPUS EUROPE explained that all activities in which we took part were critically selected, so that we attended events that truly directly connect with our purpose and strategies. In most cases, costs were funded by those inviting us; in some cases, we fund it ourselves because we strongly felt it critical to be there. Anne then shared our experience with the Workshop LUPUS EUROPE organised on research, a multi-reach workshop including a Web Meeting with doctors from medical board and beyond, a face-to-face meeting with sponsor representatives, another with Other Patient groups, and extra feedback collected from our members. This work was pivotal in designing our Strategic plan.



LUPUS EUROPE was also invited to the OECD Health Policy Forum on "People at the Centre: The Future of Health". The meeting gathered Health Ministers, companies, policy makers, doctors and a few patient organisations from around the world – some POs as speakers. All talks had a patient-centric message: Ask the patient, involve the patient, get patient-reported outcomes... Anne came out of that event with two quotes that she wanted to pass on to the group: "The only definition of a successful health system is one that produces value for patients. We must establish global standard sets of outcomes, condition by condition. There is no excuse for inaction," (*Michael Porter, Harvard Business School economist and professor*), and "Doctors have to get off their pedestals and patients off their knees"!

Jeanette Andersen followed with another significant political engagement: meeting at EULAR with representatives from WHO, the EU Parliament, the EU Commission, and all 3 pillars of EULAR. WHO insisted that (1) fighting obesity and increasing physical activity is key to prevent RMDs and (2) staying in the workforce crucial. EU Parliament delegates raised the big problem of identified budget cuts. Health research (investment) should be a big priority in EU, but is not after horizon 2020. PARE pleaded that Patients should be included in all research cycles! Health Care Professionals asked for a more holistic view of patients, that includes exercise, activity, education, self-management etc. The Scientific society presented the RheumaMap, insisting on early diagnosis, prevention, visibility and reintegration of individuals into society.

Kirsten Lerstrom was also involved with the EU Parliament: Leveraging the EULAR established EU parliament interest group on RMD's, she gave her perspectives on improving access to care during a meeting on "Policy Issues and Challenges in the Treatment and Care of Rare Diseases". She also presented at ENVI (the committee of the European Parliament on Environment, Health and Safety) on "Prevention and Treatment – the case of lupus".

Finally, this year saw the launch of European Reference Networks, where Sara Badreh, trustee LUPUS EUROPE, will represent Lupus patients in the ERN meetings.



Jeanette Andersen closed the session with the 3rd step of the "Back to Exercise" session, more intense than the prior 2 short sessions, with exercises geared towards people that can stand.

Sharing by Lupus Cyprus

By Erato Erotokritu and Chrystalla Christoforou, Cyprus delegates

Lupus Cyprus organized several events of interest to our members: Just after our last convention, they held



a workshop on the treatment and management of pain for lupus patients. A specialized pain doctor presented the various aspects of pain, and the various methods of coping and managing pain. A physiotherapist showed practical measures and ways of dealing with pain. It was a very interesting and interactive workshop which gave their members practical information on this day to day issue.

Last May they organized a brainstorming session with a Rheumatologist, with an open discussion, free expression of ideas and personal experiences. Finally, last month, they organized a very successful workshop in which a Neuro-Linguistic Programming

therapist addressed the subject 'knowing the power of your mind and your colorful energy'. Improving the quality of life of people with Lupus and promoting positive thinking, self-management and personal development is at the core of Lupus Cyprus' actions.

Pain, Fatigue and Stress – Beyond Biologic aspects

by Bernadette van Leeuw, Chair Lupus Belgium French speaking group and psychologist

In lupus, pain, fatigue and stress (PF&S) can come from the disease itself, the treatment or its side effects, but also sometimes, even when lupus is in remission and no damage exists, PF&S subsist... why?

Bernadette's presentation started from non-Lupus specifics to highlight how different factors play a role in PF&S experienced by lupus patients in remission. PF&S have at least 4 components: Biological (discussed above), psychological, cognitive (the role of the beliefs) and socio-cultural components.

Taking the example of pain, an example showing the psychological dimension is heavily injured soldiers at war continuing to run without experiencing pain because heavy stress can diminish pain. The cognitive component is about how beliefs play a role in the experience of pain. As an example, a study showed that



when people are asked to stay in a room that said to be exposed to electromagnetic waves, those that have been viewing just before a film highlighting the negative effects of the electro-magnetic waves will face more

symptoms attributed to Wi-Fi exposure than the reference group. Finally, pain has also a cultural component, coming from your education, reference group, religion, ... A typical example here is that 100 years ago, women of the high society in Europe would stay in bed up to 3 weeks after giving birth, while some African women would be back at work in just few hours... Finally, Bernadette explained the concept of “allostatic charge”, critical for chronic diseases: the wearing out accumulates during patient’s life and that may diminish someone’s ability to cope with problems. Pain itself can be a cause of subsequent pain. That is why it is necessary to act to prevent PF&S as soon as possible.



Based on what can be done when giving birth, Bernadette highlighted how all 4 components are used to improve pain outcomes: Biological (epidural anesthesia), psychological (relaxation therapy, self-hypnosis), Cognitive (good information, no insistence on perinatal death), and cultural (as talked above). To illustrate the “allostatic charge”, if you have ten children and the first deliveries have been a nightmare, the other ones are more likely to be more painful!

The same 4 components apply to Fatigue and stress. Most studies show that fatigue in lupus isn’t related as much to disease activity than it is to anxiety, depression and insomnia. Another factor to include is the nocebo (a reverse placebo) effect: If a doctor tells patients that fatigue is a possible side effect of their medication, patients report more often fatigue. So, the more we say that it is normal to experience fatigue because of lupus, the more people will actually experience it.

While PF&S are consequences of all chronic diseases, they are particularly frequent in lupus, probably because of psychologic and cognitive aspects specific to lupus.

Every symptom can possibly be due to lupus. Even if 50-75% of adults faced headaches, a lupus patient can fear it is a symptom of lupus. Chest pain can be panic attack, pleurisy, ...or lupus... That is why lupus is so frightening: at each moment, it can be lupus! This does trigger stress, and affects fatigue and pain...

The information available on Facebook or the web also triggers nocebo effects: A patient experiencing mild skin lupus, will read stories of others that have very severe lupus since years and could easily conclude that she also will suffer from all those problems...

The lack of empathy, due to low awareness, results in lower social support, triggering stress and fatigue. But



also, some people who know lupus (even doctors) have old representations of the disease. They don’t know that nowadays, it is possible for most lupus people to have a nearly normal life, and transmit their anxiety to the patients. So, lupus patients must cope with a very frightening disease, with low social support, while social support is important in coping with a disease! On top of that, they read day after day horrible Facebook stories about lupus! Of course, people that are doing well with their lupus are not as active on the web... From a psychological point of view, lupus can really be a disaster!

Why more people with lupus ?

- Everything can potentially be a symptom of lupus
- Some lupus forms are frightening : One word for very different diseases and all patients mixed on Facebook !
- History of very poor treatment results, substantial « recent » progress are little known (Schneider : 90% respond to the treatments)

On the cognitive side, we, as patient's organisations, are responsible to give balanced information. Insisting on PF&S elements of lupus make these even bigger for readers. HIV Campaigns don't say that 1/8th of late diagnosed patients will die within 4 years, rather they insist on prevention, screening and treatment, ... and on living a normal life with AIDS. In contrast, with an objectively less severe disease, we talk of "invisible monster", "a disease that takes the control of the life of the patients". Is that helping people? We sometimes unintentionally increase the anxiety of patients by giving them a catastrophic view of the disease. Remember, when you tell people that they will suffer, they are more likely to suffer, and their suffering will be bigger. Do we want to confirm patients in their status of poor victims of a horrible disease? Or to say: "Good news, if you adhere to treatments, you can live with your lupus!"



As patient organisations, we can help our members deal Pain, fatigue and stress by touching all 4 aspects: On the biologic side, we can encourage people to adhere to treatment, explaining why it is so important; On psychologic aspects, we must provide support by listening with empathy, respect and kindness, then, after



listening, boost our members by considering them as responsible adults, not powerless victims. We must tell them that they have in themselves the power to fight, and build their confidence that they can win.

On cognitive aspects, we must say that when lupus is in remission, it is not normal to be tired and to have pain, inviting patients to search for the cause of such symptoms outside lupus. We must reduce anxiety by putting back dramatic and negative information in its place and by showing patients that nowadays, lupus can be put under control.

And we must promote physical activity - the only strategy proven to work in case of lupus-, and more generally, self-care and active coping strategies against PF&S. These have been proven to be more efficient than rest and

massage.

Bernadette concluded that Patient's organisations are like tightrope walkers as they must say (1) that lupus is a severe disease and so, patients must take their medicines, (2) that 'old' patients have lived a real nightmare and that still now, they suffer a lot from the consequences of the lupus or its treatment, and also (3) that lupus can be coped with in the very vast majority of cases and that patients are not condemned to be stressed, in pain and tired. It's a tricky job, and not one that will make you popular, but it's worth it!



After Lunch, we gathered for a guided tour of Milan, starting with the Forza Castle, walking through the Cathedral and the Scala, and coming back by bus through the modern Milano and its business quarters.

Kirsten Lerstrøm introduced our 3rd convention day welcoming our Italian Doctor friends.

Lupus Italy – 30Years of Patient Association

By Augusta Canzona, Chair Lupus Italy



Augusta presented a short history of the Italian group, created in 1987 and founding member of ELEF (now LUPUS EUROPE) in 1989. Over the years, the group has continuously grown in regional coverage and membership. Its magazine, ICARO, created in 1991 is still a main source of information about the disease and the SLE Group activities. Since the 90's, Lupus Italy is very involved with medical institutions, leading to the creation of Lupus clinics and Doctor-patient meetings being held in the major Italian hospitals.

Lupus Italy has many achievements they can be proud of. Next to the usual activities of lupus groups, they are extremely active in supporting research, with 15 scientific research projects funded, 7 Lupus Clinics, special support for pregnant women, a Pilot Project on Psychological Counseling, and covering expenses for 82 young doctors to attend training courses and/or international meeting on Lupus. This is in part

possible thanks to Italian law that allows taxpayers to turn over 0.5% of their taxes to non-profit organizations.

Italian Projects

By Augusta Canzona, Chair Lupus Italy, and Davide Mazzoni, LUPUS EUROPE PRP

In 2015, Lupus Italy's online survey on "unmet needs of patients with Lupus" highlighted that healthcare models do not meet patients' complex needs, strongly affecting quality of life and patient-physician relationship. Over 80% reported bone and joint pain as the main symptoms and continuous pain burden, affecting working life. Prejudice on SLE still exists, and stress is one of the most important factors jeopardizing illness trend.

Davide Mazzoni then showed key outcomes of the 2017 survey "at home or in hospital?", an Italian survey on preference for subcutaneous injection at home vs. intravenous infusion in hospital for biological treatments of SLE. The on-line anonymous survey covered 548 participants (96 % Female). Most age groups preferred subcutaneous vs; Hospital Intravenous except patients >43 years and patients who had experience of biological treatments which were neutral between both options. That group felt the safety provided by the presence of qualified staff was more important than the benefit of staying at home. For those preferring subcutaneous, the key reason is the avoidance of a work day loss, the distance of the hospital, and the increased autonomy in managing their treatment

Results
Reasons for preferring intravenous infusion

Word	Total occurrences	Occurrences in the sample of patients who prefer infusions
sentire / to feel	54	42 (87.04 %)
controllo / control	22	21 (95.45 %)
personale / staff	19	18 (94.74 %)
tranquillo / quiet	19	18 (94.74 %)
medico / doctor	24	21 (87.50 %)
effetto / effect	19	15 (78.95 %)
pausa / fear	9	8 (88.89 %)
puntura / puncture	22	16 (72.73 %)
infermiere / nurses	10	8 (80.00 %)

Versus previous studies, which showed a higher percentage of preference for the auto-injection, results difference might come from the fact this study was about a hypothetical preference without direct experience of subcutaneous injection of biological therapies. The team was surprised that many patients expressed

Reasons for preferring subcutaneous injections

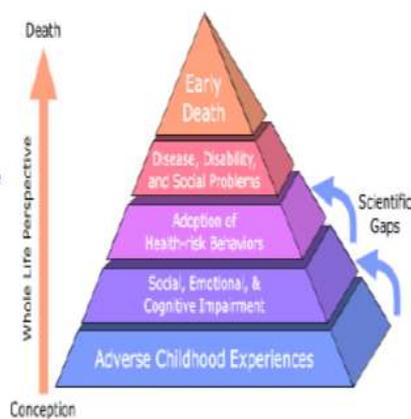
Word	Total occurrences	Occurrences in the sample of patients who prefer subcutaneous injections
comoda / comfortable	26	25 (96.15 %)
comodità / comfort	23	22 (95.65 %)
ospedale / hospital	95	69 (72.63 %)
casa / house	36	30 (83.33 %)
lavoro / job	13	12 (92.31 %)
tempo / time	30	23 (76.67 %)
gestire / to manage	14	12 (85.71 %)
evitare / to avoid	19	15 (78.95 %)
praticità / convenience	11	9 (81.82 %)
cura / care	11	9 (81.82 %)

preference for infusions at hospital, emphasizing the importance of safety feelings. The study concluded that individual preferences and motivations should be carefully considered to adopt the delivery model that will fit each patient.

The audience highlighted that studies on how the frequency of injections vs. infusion, and the lower control could impact adherence would be highly welcome to complete the decision making.

Kirsten noted that the EMA authorization site provides very valuable information (http://www.ema.europa.eu/ema/index.jsp?curl=pages/medicines/human/medicines/002015/human_med_001466.jsp&mid=WC0b01ac058001d124)

Another study, by Marina Falanga is still on going, focusing on early stressful events in life as predictors of SLE progress, and the role of psychological assistance. It considers how adverse childhood experiences (ACEs) play a role in how the disease expresses itself in adulthood. Stressful events are related to immune changes and play a role in onset, progress, and exacerbation of autoimmune diseases, including SLE. Physiological and biomolecular studies are establishing how childhood exposure to chronic stress, leads to changes in the development of nervous, endocrine, and immune systems, resulting in impaired cognitive, social, and emotional functioning and increased allostatic load (i.e., chronic physiological damage). Recent data suggests that disorder in the affection regulation may be a key feature in SLE; in that it may increase perceived stress and influence the intensity or the duration of physiological stress responses.



Traumatic stress appears to be lifelong because it remains “recorded” in the body, self-perpetuating in unregulated biological systems. There are striking analogies between neurobiological correlates of early-life stress and inflammation. This could mean that treatment for patients with a history of childhood trauma could be improved by integrating medical and psychological dimension, providing a more complete picture of health determinants that are not usually assessed. Both trauma based psychological treatment and rethinking of the physician-patient relationship may be important adjuncts to traditional medication for patients with SLE.

LUPUS EUROPE New Website

By Katharine Wheeler, Vice Chair LUPUS EUROPE

Katharine led us through the prototype of the website, highlighting some of its key features. Thanks to Setfire.to’s pro bono work, we will benefit from a much modernized visual and access to information experience. The website will be live shortly, and we will then host a webinar on how to use it. Katharine showed how members can contribute by supplying asked information or exchanging documents. The web site will contain a sharing section that will only be worth what members will do with it. Even if documents are not in English, members are encouraged to share: it is better to share “native language” documents (research they run, events, ...) with a few opening words in English rather than not share. Participants welcomed the group sharing feature. This is truly something we must build on. The session ended with a unanimous appreciation of the new website design, and a round of applause for the new logo designed.

Tai Chi

By Alessia Sarrapochiello, Living with lupus in Italy.



After an introduction to the history and benefits of Tai Chi, 3 Tai Chi teachers demonstrated how Tai Chi can be practiced moving, standing or sitting, with a beautiful and inspiring choreography. We then shifted to practice, experiencing ourselves how Tai Chi can help us reduce stress, finding balance and relaxation. The session was concluded by a beautiful testimony from Alessia on how Tai-Chi helped her Kick Lupus and live a better life.

Future conventions

By Alain Cornet, Secretariat – Lupus Europe

Conventions compose a significant part of LUPUS EUROPE's spending, equivalent to 3 patient panels... In view of our Social responsibility to use our funds at best in the interest of our charitable aims, the board considered how we can optimize this cost, while making it possible for a maximum to participate.

To reduce costs, we will shorten the convention, making the sightseeing optional on day of arrival, eliminate gifts, and seek Early bird payment to lock in lower room costs. We will increase base price for members that "just want to attend" by charging true cost, but offer lower cost than today in exchange for higher involvement. This will be achieved by Early Bird payment, Twin room discount, and a Member Active engagement discount earned during the year by answering Surveys & Email queries; disseminating LE info to members; referencing LE Blog & Web on national webpages and attending a lupus Chat. Net, members will be able to reach prices as low as 150 € for 1, 200 € for 2 instead of 500 € today.

Further, we are looking at creating synergies by holding a Patient Expert Group and possibly a Working Group meeting the day before or after the convention, or having industry funded panels the day before.

All in, this will maximize the value for money of our conventions, ensuring active participation, disseminated results, increased networking opportunity, and saving on overall travel budget.

Participants highlighted that some countries that have sufficient funding could help others join by giving up their discount in their favor, creating a true solidarity. Also, they suggested that web based seminars could appropriately complete our connection opportunities. This is an activity that is planned next year, and we hope will achieve good success.

Country Sharing from the Netherlands

By Wendy Zakouris, Treasurer NVLE

NVLE groups people with Lupus, APS, Scleroderma and MCTD, and has a specific committee dedicated to Lupus and APS. They have 2250 members and next to patient support activities are engaged in research, including holding DAiRE registry, supporting Lupus Nephritis study, and launching a Youth group.

They just ran a Plaquenil survey on line, which showed (preliminarily) that out of 954 participants to date, 232 have a dose > 5mg/kg and 208 had a dose > 5mg/day in an earlier stage and were lowered sometimes or don't take it. Final results will soon be



Page 17 of 24

available. On that base, NVLE will work with doctors to better spread the guidelines and get new guidelines on eye doctor visits.

Country Sharing from Portugal

By Ines Ribeiro and Altiva Paula, Delegates

Lupus Portugal celebrated its 25 years this year and organized various events such as the 2nd Lupus Running and an annual Patient meeting focused well-being guidelines. They benefit from tax deductible donations and made small cards to remind people to donate. This resulted in a significant growth in their income. They also collaborate with restaurants & Cafes that are using Lupus awareness paper sheets on their trays.

Ines invites everyone to share their best practices with others to create synergies, and provides a number of suggestions on things that we could do: A welcome kit for new patients; an App that would be informative, organized, with useful facilities to help on daily issues; gathering statistics & facts about Lupus in Europe; creating a LUPUS EUROPE Award for research, A database of research, studies and trials or a platform to share Good Practices.



Those great suggestions are welcomed. Some are covered by the strategic plan, but more can be done. Our limit is the human resources capacity, so all are invited to participate in leading or working for such shared projects.

After lunch, Anne introduced the afternoon with a short Mindfulness session. Mindfulness is an active coping strategy that can truly help long term to handle Pain, Fatigue and stress.

Lupus Clinics

Session chaired by Augusta, Chair lupus Italy

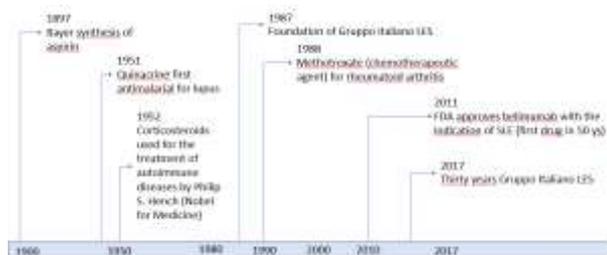
Lupus Italy is funding 7 Lupus Clinics in Italy. These are centers where a multi-disciplined team opts for multilateral communication and a patient-oriented approach. The center becomes a single point of contact to the family doctor, a help-desk, a priority access for emergency assistance, and offers access to new, off-label treatments.

The use of Biologics in the treatment of Lupus

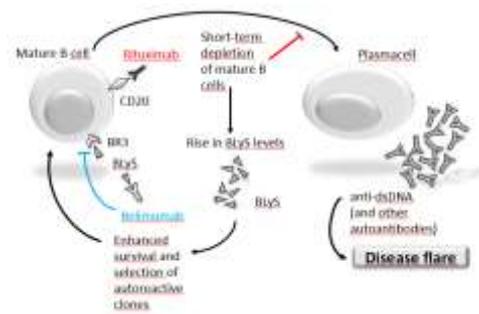
Dr Gualtierotti – Lupus Specialist at Milan Lupus Clinic

The Milan Lupus Clinic receives people with Suspected SLE, anti-phospholipid syndrome, undifferentiated connective tissue disease (UCTD) and SLE-like UCTD.

After a brief overview of the evolution of treatment of Lupus, Dr Gualtierotti discussed the perceived issues of Biologics. Biologic drugs are substances made from an organism or their products developed to directly target molecules thought to be involved in the inflammatory process. In the last decades they provided a real breakthrough in Rheumatology and have been used in successfully in several disease areas.



Yet, patients have resistance. There is the fear of being a guinea pig – but the biologics used in lupus have a long history of usage in other disease areas... Biologics are as safe as traditional medicine that act on different levels of immune system with no specific target. With Biologics, we can target B-cells before they create damage. This is a good example of translational medicine, carrying scientific knowledge "from bench to bedside". From basic research advances (studies of biological processes using cell cultures) they allowed to develop new therapies or medical procedures.



Dr Gualtierotti conducted research on successful sequential therapy with rituximab and belimumab in patients with active SLE. These molecules work on different B-cells, so will be effective in different cases. In conclusion, Dr Gualtierotti told us not to be afraid of taking care of ourselves, of asking about our illness and our treatment, and that treatments are safe. Before a drug reaches the market and obtains new indications many years with many studies pass, and then, the drug is still under strict monitoring!

Family Planning issues in Lupus Clinics

By Dr Fredi and Dr Nali, Lupus specialists at Brescia Lupus Clinic

In Brescia, Lupus patients can contact doctors by mail or telephone, and a complete set of specialists is available to them in the outpatient practice. The clinic has more than 300 patients, 45 of which under Biologics. Through 2016, they had 142 patients followed during pregnancy.

A particular care is going to family planning issues, because women with rheumatic disease have lower number of births, reduced period of fertility, longer inter-pregnancy interval, lower proportion of women achieving a subsequent pregnancy and a higher number of miscarriages. The Lupus Clinic ran a survey on pregnancy and family planning issues for rheuma patients. They found that 30% of patients have never been asked about their desire to have children. They also identified that more than half declared that reduced the number of children they wanted. Patients frequently declared that they were afraid of not being able to take care of children, but also that disease or drugs could harm the baby or that babies could later suffer from the same disease. It's important to underline that these two issues are linked to poor knowledge and could be overcome with adequate counselling! They then considered counselling on contraception and found that 60% of SLE/APS women did not receive a counselling from rheumatologist, even if this topic has a great importance in the management of these patients for the effects of estrogens on disease activity.



PREGNANCY

Breastfeeding

Remember: in many cases, a drug is contraindicated because there is lack of information and not because of a proven contraindication!!!

After showing that the risks involved in pregnancy with Lupus have been very sharply reduced (maternal death down to 0.17% vs. 17% in the 50's), Dr Fredi highlighted the results of 132 maternities followed in Brescia. SLE flares occurred in 57 % of the cases, the vast majority being mild flares (74 %). They then identified that some biological parameters can be used as Predictors of LUPUS flare risks during pregnancy. By following these parameters to plan a pregnancy, risks can be sharply reduced.

The team then designed patient oriented guidelines and advise for pregnancy planning, stressing the key role of pre-conceptional visits, drugs allowed/contraindicated and

fighting “unrealistic fears”. Dr Nali stressed that in many cases, a drug is contraindicated because there is lack of information rather than a proven contraindication!

The dialog with a multidisciplinary team is fundamental to manage and treat patients before, during and after pregnancy.

Unmet needs and quality of life in Lupus Patients

By Dr Fulvia Ceccarelli, Lupus specialist at Rome Lupus Clinic and Living herself with lupus



Patients are usually referred to the lupus clinic by their GP, other patients, or simply come via the website. They are usually examined within 10 to 15 days. Clinical and lab data is collected in a standardized form and other specialists are involved as needed. At the end of the examination, the next appointment is planned. Typically, visits are scheduled quarterly, unless disease activity or complications require more visits. Between visits, patients can contact the clinic by phone or email.

Dr Ceccarelli addressed the subject of “unmet needs of lupus patients”. Dedicated clinics, providing staff with specialised experience and targeted training allow an early diagnosis, but also a better access to treatment as they have easy access to new therapies, and the follow up of comorbidities and complications is better managed. The multidisciplinary approach allows to integrate all services to Improve quality of life, such as a call center, psychological support, or contacts with patient organisations. The clinics also focus on the higher needs of patients on the Maslow scale.

The survey on unmet needs reflected that patients want to be recognized as “normal people” not a rare species, to be listened to by doctors, and to live normal lives, without pain and extreme fatigue. As a result, doctors and patients should jointly ensure that every visit addresses the person and the illness by considering not only the organic disorder but also the affective and emotive components that participate and affect the pathological process. This requires to build communication skills. Dr Ceccarelli then insists on the trust that must exist in the patient/doctor relationship. This trust will drive long term better results thanks to higher adherence and better reporting of Patient outcomes. This then improves Quality of life. EULAR recommended that a complete assessment of SLE patients includes not only the evaluation of disease activity and chronic damage, but also of quality of life (QoL). The LupusQoL has recently been developed and validated in the UK. When tested with 117 SKE patients in Italy, the LupusQoL questionnaires showed its ability to discriminate SLE patients with different level of disease activity.



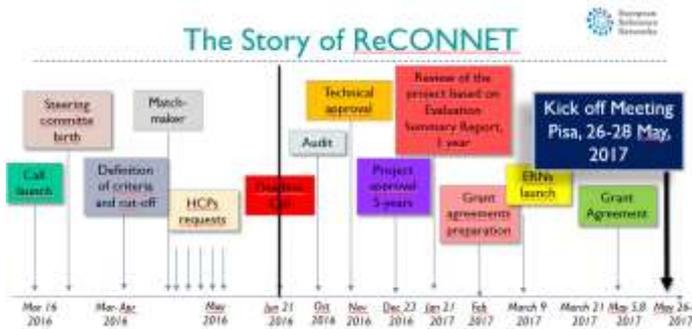
The ERN, ReCONNET

By Professor Marta Mosca, Reconnet leader

ReCONNET is the European Reference Network (ERN) handling Rare and Complex connective and musculoskeletal diseases. It started in June 2016 by establishing a recognized network. This required at least 10 Healthcare Providers located in 8 different Member States to jointly and individually apply to create the ERN. Each Thematic ERN must ensure continuity of care from pediatric to adult care. Patients and patient

representatives must play an active role in the decision and opinion making process of the ERN and be involved in structural and clinical network activities.

The objective of the ERN is to facilitate access to better and safer healthcare, define proper organizational assessment and identify standard and cost effective pathways for the management of the diseases. The aim is to reduce disparities of treatment. This does not mean that everyone will have the most expensive treatment, but that the right treatment goes to the right patients.



The first Steering committee defined access criteria to be recognized as network member. These include having enough patients, a multidisciplinary approach, demonstrated expertise through research/publication, ... Each participant had to obtain national health ministry endorsement. A lot of material was collected to certify the expert nature of the candidates to the excellence network. The criterion had to be strict because all centers will be audited by the EU

within the 5 years of the ERN.

The EU ERN grant merely pays for travel and project management, but being recognized is a high stake political item. It brings visibility to the work, the goals, etc.

The objectives of ReCONNET are multiple. It will seek to facilitate information sharing, as well as patients and health care professionals movement across borders. This will not mean that patients will have to travel around, but rather that information, imaging, tissues will be traveling across borders to ensure correct diagnosis, discuss complex cases and improve treatment. Today, this relies on the personal connections of your doctor, in the future the Network will allow any doctor to reach experts by simply reaching out to the ERN. The French system of “filière”, whereby hospitals work as networks, is a good example of how we should work in the future throughout Europe.



The potential of better knowledge sharing is high: if we could pool the data of all people in Europe, we will have an incredible step change in the knowledge of the disease. Yet, research is not the key focus of ERN, which is more focused on treatment. In this respect, one of the goals will be to optimize available resources, avoiding waste by better targeting treatment.



One of the key mode of actions of the ERN will be to develop recommendations and quality guidelines. This is not just for treatment, but also information and recommendations for patients. What we have today are in most cases are suggestions: recommendations require us to go further and to base ourselves on literature review and scientific facts. Patient groups must progress on that, moving from “common sense” suggestions to fact-based recommendations.

Finally, one of the objectives of the ERN is to empower patients in the management of their disease, which requires listening to each other, but also growing our knowledge of the disease.

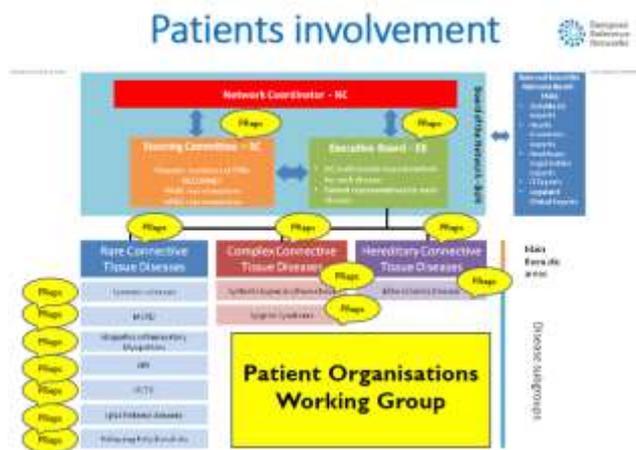


26 clinics are now included in the ERN. Many are not on the list because the doctors simply did not apply, but are actively involved. This is an inclusive approach. The ReCONNET network is built on two dimensions: geographic and disease. For each covered disease, there is a medical coordinator and a patient coordinator, from a European Organisation. For Lupus, Sara Badreh, from LUPUS EUROPE is the patient coordinator and is member of the steering committee of the ReCONNET network. Next to the disease specialty network, we will also have experts in technical areas (registries, genetics, economics...) across various disease areas.

The network is progressing very well. A review of existing literature to identify recommendations and guidelines for the various diseases is currently in progress. Once identified, the results of this review will be published. The next step will be a survey to understand if and how those recommendations are applied. Some doctor's guidelines are very good and will be endorsed, some will need to be updated. Others are missing, but data exists, and recommendations can be developed; Finally, some areas have no data at all, so no recommendations can be made, and the role of ERN will then be to collect the data. That will take a lot more time.

There is also a need for patient involvement in the platform. This will be the place where issues can be discussed, and having patient's involvement will be key, as patients will also call into the platform for support (not to replace their doctor, but for patient focused questions).

Marta closed thanking all for their participation, and urging us all to actively engage when the Network will call for additional support.



In the evening, we enjoyed a special dinner in the Milan city center, with live music. This was the occasion to recognize Yvonne and Peter Norton (this was their last convention), as well as Kirsten Lerstrøm, exiting chair of LUPUS EUROPE for her 6 years leading the group.

Sunday, November 19, 2017

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.

Jeanette Andersen, Secretary of LUPUS EUROPE opened the session, verifying quorum, and distributing the voting forms to delegates. Katharine Wheeler and Annemarie Sluijmers, candidates for the 2 open trustee positions briefly introduced themselves. Both Trustees were unanimously elected.



Jeanette presented the proposed amendments to the constitution, which all focused on the bodies that support the action of the board: Co-opt advisors, Medical Advisory Board, and General Secretary. By recognising the critical roles and mandates of these three important groups of people, the goal is to empower them to act and bring value to LUPUS EUROPE, helping us to steer all resources and enthusiasm available to achieve our goals. All articles were approved by the Council at a very large majority, no votes against.



Chair Kirsten Lerstrøm then reported on past year's activities, and Treasurer Kirsi Myllys on Financials, which were approved. LUPUS

EUROPE is in good shape, both in terms of being active and in terms of financial health.

Jeanette Andersen then covered LUPUS EUROPE priorities for 2018. These will follow the new strategic plan 2018-2023 that we worked on during the convention. As we did last year, we selected big rocks that we will focus on:

- On Strategic driver 1, "People with lupus in Europe participate in, and benefit from, lupus research", we will focus on (1) Launching the Patient Expert Group acting as liaison and resources on research and clinical trials (2) Run a patient panel on Youth in Spring 2018.
- On Strategic driver 2, "Member organizations are enthusiastic and empowered", we will focus on (1) Making next year's convention equally as memorable as this one in Milan, with an additional focus on ensuring that it is effectively relayed in our national groups (2) Actively engaging members in projects and networks. This will need collaboration of our members. We have projects planned in this area to share how we can ignite lupus Youth groups by building on each other's experience. Jeanette encouraged everyone to share the material, video's testimonies, ... that can be shared with all.
- On Strategic driver 3, "LUPUS EUROPE is heard and acting", our focus will go to (1) Modernising our Web presence (2) Defining Clear messages and designing toolkits to communicate them to each key audience.

Jeanette Andersen and Kirsten Lerstrøm closed the council session by thanking the Italian team for a great convention.



Message tracks Training

By Alain Cornet, secretariat – LUPUS EUROPE

As last item in this convention, Alain Cornet led us through a training on "Message tracks". As Lupus community leaders, we regularly speak in front of small or large groups. While presentation skills are critical

to deliver a message well, something else is even more critical: defining WHAT we want to say. We can all gain substantially in impact by clearly defining the objective of our communication, and from there, structuring our message to bring our audience straight to the point we want to make.

Alain then showed us how it all starts by defining the communication objective. This is not what we want to communicate as knowledge, but rather what we want our audience to do or to think when we have finished our talk. This is not easy, but is crucial. Unless we have clearly defined that objective, it is impossible to define how we reach it. He then guided the group through the 6 steps to build the communication backbone that will deliver that objective:

- Brainstorming all messages that could help us reach it,
- Eliminating those that are counterproductive,
- Organizing and summarizing the selected ones
- Checking if they are sufficient to achieve the objective
- Enhancing them further, and finally
- Testing, aligning and using them.



Alain explained how this technique can be used also to clarify our thoughts when we have a complex idea to present, or to reach alignment in the board about any complex topic.

The attendants then split into 3 small groups to test themselves the first steps of this methodology.

Close of Convention

After a short debrief, Kirsten Lerstrøm then closed the convention, thanking all for their engagement, and announced that next convention will take place November 22-25, 2018 in Belgium.

