



UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

"Treatment and patient involvement"

LUPUS EUROPE Convention 2016



LUPUS EUROPE's 2016 convention took place in Würzburg, Germany, and was centered on the theme of "Treatment and patient involvement". Lupus is a disease characterized by an overactive immune-system that needs to be controlled. To this date there is no cure and no single biomarker or treatment option available to really kick lupus away. It is LUPUS EUROPE's firm belief that identifying and developing treatment options with a better perspective than today will require patients and patient organizations' active involvement.

Our convention took place at GHotel Würzburg, where participants gathered on September 28th for a Welcome dinner before the start of the Program on September 29th. We are really very grateful to Simone Pretis and Borgi Winkler-Rolfing, Lupus Germany, for the preparation and for hosting 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 several 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 to our members at <http://www.lupus-europe.org/members-area/conventions/wuerzburg-2016>]

Thursday, September 29, 2016

Opening session – Welcome

Anne Charlet (Vice-Chair of LUPUS EUROPE) welcomed all participants and highlighted that the convention would also be followed on Facebook and Twitter. Borgi Winkler-Rolfing (Chair of Lupus Germany) then extended her welcome, wishing us plenty of new learning and friendship, and inviting everyone to the 30-year celebration of Lupus Germany that would take place on Saturday. Kirsten Lerstrøm (Chair of LUPUS EUROPE) followed, introducing



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St. James House, 27-43 Eastern Road, Romford, Essex, RM1 3NH, United Kingdom - REGISTERED CHARITY NO.: 803768

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the trustees and co-opt advisors and presenting the overall convention theme and agenda. Finally, Simone Pretis (Vice Chair of Lupus Germany, and Co-Opt advisor of LUPUS EUROPE in charge with the Convention) shared logistics details, and explained that she and her team would be on hand so that we would all feel comfortable. Petra Balazova (Slovakia) then guided us in the first of a series of physical exercises adapted to people with lupus, a practice she helped us maintain with regular short physical exercise sessions throughout the convention.

Patient involvement, now!

By Camille Bullo, Membership & Stakeholder Relations' Manager, European Patient's Forum (EPF).

EPF, as a non-governmental advocacy organisation represents the collective patients' voice at EU level, pursuing the objective that all patients with chronic conditions have access to high quality, patient-centered equitable health and social care. Their work is centered on 6 essential goals: Health literacy, Healthcare Access and quality, Patient's involvement, Patients' empowerment, sustainable Patient organisations and non-discrimination. Over the last few years, they have added a Capacity Building pillar, offering participative training and experience sharing, which LUPUS EUROPE and member groups have often actively participated in and benefitted from.

Patient involvement in health care should be something that is obvious. This is both for accelerating valuable innovation (addressing key patient needs and enhancing quality of life) and to be part of the necessary social change! To drive change at EU level, patients should be involved before the Commission drafts any proposal, and until full implementation locally. EPF can help talk to the Commission and the 30 MEP's of the Parliaments' "Environment and Health Commission". National organisations have a key role to motivate and support their MEP's and follow up with national governments, on which European umbrella organisations have no impact. We all have a role to play! Recent successes include the directive on pharmaco-vigilance and the involvement of patients at the EMA (European Medicines Agency), creating a Consumers' & Patients' working party, where patient input is taken into account



EPF also supports the involvement of patients and patient organisations (PO's) in research: we have more to bring than body fluids and tissue. We have unique insight into the "real lives" and "real needs" of patients that must be used to influence gap analysis in research priorities, clinical trial design, Quality of Life (QoL) measurements or value of new therapies. Patients are experts that should not be ignored, because they have experience that others cannot match. EPF has developed various work-streams to support PO's in meeting the unprecedented level of change in the research area (big data, genomics, clinical trials, ...). To serve and prioritize so many requests, EPF assists PO's in building both capacity (funding/resourcing) and capability, to move from being a subject of analysis to being a reviewer, then co-researcher, and ultimately a driving force. Examples include the recent workshops on Communication and on Transparency/Ethics. EPF also runs programs on the web (www.eu-patient.eu).

Now that patients have a seat at the table... there is the issue that many seats are empty. Consequently, EPF, along with universities and pharmaceutical companies developed the EUPATI (European Patient Academy) program (www.eupati.eu), providing face to face and web training, but also multilingual toolkits to reach thousands of patient advocates and train them on medicines development, jargon, knowledge, ...

Not everything is done, many questions remain open, including how to avoid the building of patient capability inadvertently becoming a barrier to involvement, or how to avoid tokenism rather than true meaningful involvement, or how we move from “shaping the patient to suit the system” to the other way around. We are all invited to take our seat at the table where this is happening!



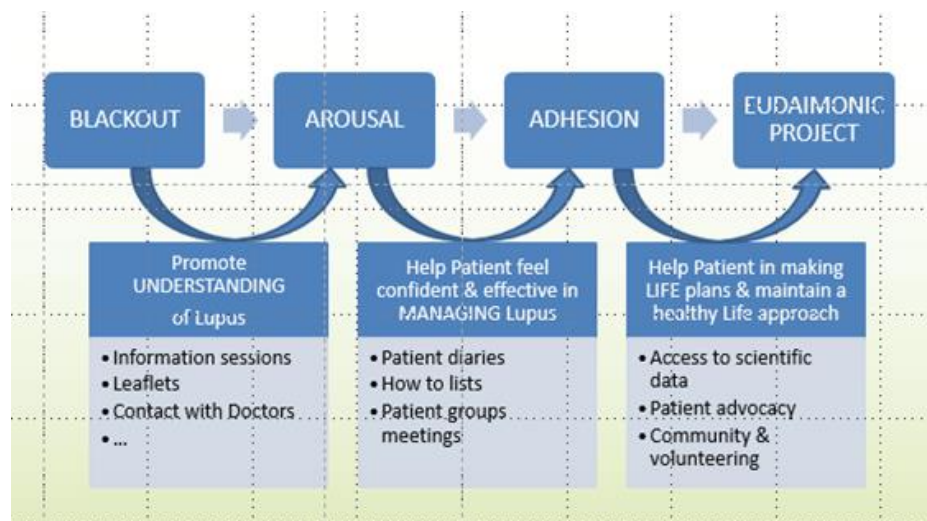
LUPUS EUROPE Patient's Panel

By Alain Cornet, Secretariat LUPUS EUROPE



Starting from Helsinki's 2014 Convention, LUPUS EUROPE has engaged in Patient Panels to better understand the subject of treatment. The first step was to define treatment in a way that people living with lupus understand it, i.e. “Any product or activity that aims at improving the person with lupus' quality of life”. We then explored the difficulties that people with lupus face particularly with the inadequacy of treatment, or the obstacles when adhering to it. This led to the writing of 3 letters addressed to fellow patients, patient organisations and the medical community. In March this year, a new panel took place. Its objectives included the collection of quotes from panelists that illustrate the patient's journey with lupus. They will be used by Davide Mazzoni (Co-opt LUPUS EUROPE Research Trustee) for a publication on this theme. It confirmed the working assumption that people with lupus go through 4 phases (blackout, arousal, adhesion, eudaimonic project) as they progress through the disease, and results in the need for different roles to be carried out by patient organisations, to help their members depending on where they are on their respective paths.

Another objective was to explore the key drivers of patients' involvement in Clinical Trials. Notions such as Trust, Lupus Monitoring, Better Care, and a desire to help others emerged as driving forces, with risk, side effects, and scheduling difficulties being primary obstacles.



Finally, the patient panel gathered informal feedback on the Doctor to Patient Ownership of Treatment, i.e. from all components of treatment, which elements are Fully Doctor Controlled (and largely adhered to), or Fully Patient Controlled (not being prescribed), or in between (i.e. mutually agreed, or prescribed but adjusted). We took the opportunity of the group being together to collect similar data from the

delegates. While this data is not scientific, it provides an interesting picture that could be validated by further research. As per the table below, while Plaquenil or drugs for side effects are taken “as prescribed or agreed with the doctor”, cortisone is often self-adjusted, and other items are mostly self-medicated.

	Dr Prescribed	Dr/Patient Agreed	Patient adjusted	Self-Medicated
Plaquenil	80%	20%	0%	0%
side effects drugs	50%	50%	0%	0%
vitamin D	47%	37%	5%	11%
physiotherapy	27%	55%	18%	0%
sleep aid	20%	60%	0%	20%
cortisone	13%	56%	31%	0%
massage	13%	13%	38%	38%
exercise	8%	23%	8%	62%
pain killers	5%	63%	5%	26%
vitamin C	0%	67%	0%	33%
homeopathy	0%	75%	25%	0%
acupuncture	0%	0%	0%	100%
meditation	0%	0%	0%	100%

Another quick quiz explored which source of information that the 21 participants with lupus would use if they were prescribed a new medication, unknown to them, by their doctor. This quiz concluded that almost all would “ask friends”, consult a moderated or open discussion forum, read the notice, and I “Google it” (>75%), half would ask their national PO, a medical website, or another doctor, and in the end twice as many “follow their gut” as opposed to “just trusting their doctor” if they don’t find reassuring evidence. While again non-scientific at this point, this could be worth investigating further.

We concluded the morning by a brief introduction into research, and the role patients have to play in this area. Research is moving at a fast pace, and we must get engaged. This topic became our lunch discussion topic, discussing the areas in which we should get more involved or where patient influence could help in trials.



Lupus in the skin

By Kirsten Lerstrøm, Chair LUPUS EUROPE



A [2015 study](#) among 82 experts in Cutaneous Lupus (CLE) concluded that CLE treatment is mostly based on personal experience without randomized controlled studies to back them up. The variability of answers clearly showed the need for treatment guidelines suitable for each CLE subtype. Annegret Kuhn initiated such guidelines, which have been endorsed by the European Society for Cutaneous Lupus (EUSCLE), but are not yet EULAR endorsed. LUPUS EUROPE supports the request that such guidelines be endorsed because we need standards of care in this area which affects 78% (re. EULAR Textbook 2012, p 550) of people with lupus at some point in time.

In an open exchange, members then shared their experience with access to sun protection. In Spain, a campaign offers a discount to members of a lupus group. In Denmark, the Danish SLE network in collaboration with the Danish Rheumatism Association

developed a letter of proof (signed by Danish Society of Rheumatologists and the Rheumatism Association) that most lupus patients need extra sun protection. This letter helps patients get reimbursed for part of the sunscreen price, UV clothes, window filters... On the other hand, in most EU countries, including Germany and Italy, sunscreen is considered as beauty care, which is not reimbursed, and in Sweden, authorities don't consider the sun as a big problem due to the short summer!

Kirsten then presented the SmILE survey gathering Pan-European data on information about lupus in the skin and the need to protect from UV exposure . This 39 question survey provides factual evidence on the status of sunscreen today (frequency of application, protection factors,), as well as patients' bio-demographic data and lupus histories. The objective is better information leading to better care and better reimbursement. Members are asked to help collect as much data as possible in the coming month.



Access and transparency – What we learned with EPF

By Katharine Wheeler, Secretary of LUPUS EUROPE



Katharine informed us about key developments in access and transparency, two topics where she joined the work group initiatives by EPF:

Access: The workgroup meets twice a year and, this year, published a statement on Access to Healthcare from the patients' perspective with 9 key recommendations. An online Survey on Access to Healthcare is now running (deadline 31st October 2016), in easy-to-understand English. Next year, Access will be the theme of EPF's annual campaign, focusing on the 5 A's of Access (Availability, Affordability, Accessibility, Adequacy and Appropriateness).

Transparency: Fresh from press as the workgroup met only last week, an incredibly important and vast subject, where best practices remain to be found. The workgroup defined key elements like transparency, ethics, and accountability and looked at governance aspects. Looking at annual reports and websites, the team then reviewed how EPF, LUPUS EUROPE, and the other participant groups appear to the outside world, and all realized how much work remains to be done. Finally, they considered how policies and procedures should be created on those themes, and defining priorities that attendants to the workshop can start implementing in their respective groups. Next year, we expect a brochure will be published by EPF on this theme, similar to the one made last year on Fundraising.



KICK LUPUS!

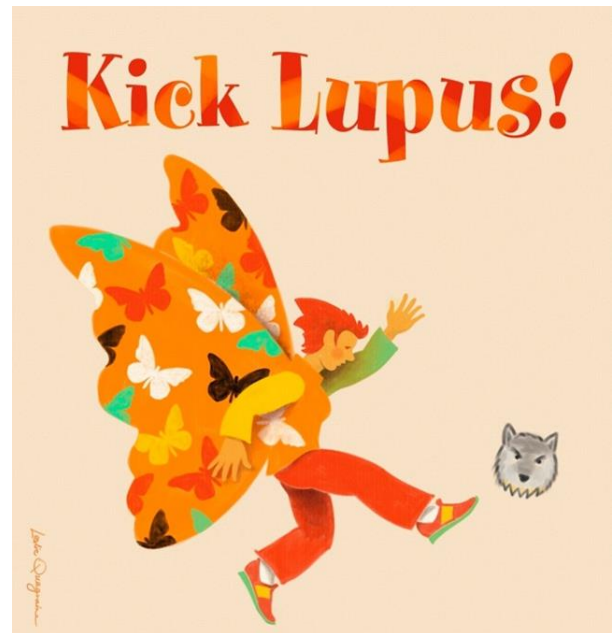
By Anne Charlet – Vice Chair of LUPUS EUROPE

Anne shared her experience in the EPF Communication Workshop held almost a year ago, and how the idea of “Kick Lupus!” as a theme for a long term awareness and action campaign emerged from the lack of awareness about lupus on the one hand, and the need to move (in all senses of the term) on the other hand. The objective is to raise awareness, provide tools for people with lupus that help them “kick lupus” even on their worst days, and provide a dynamic and positive energy that empowers people with lupus, and all those living in the lupus world, to kick it further away day after day.



Anne highlighted the work done pro-bono by Brett Kobie (from Fleishman-Hillard), defining a possible objective of providing people with a simple guide to exercise a little more today than yesterday, regardless of their start-point in physical condition. She then explained how interactions with GSK have led to the concept of “Lupus Heroes”, those people who, at their level, challenge their lupus by exercising, socializing, taking on a job, practicing a hobby, ... that requires an effort on their side, but prevents lupus controlling their lives.

The idea of Kick Lupus! was positively received by members who then engaged in a workshop, exploring how the idea could best be deployed and how it could be used with other target groups, like with doctors, or for sponsoring.



Our challenges

It is difficult to tell someone who is severely fatigued to “get active.” Bringing that message in an insensitive way may well do more to discourage them than empower them.

Lupus is a complex condition whose symptoms will not be magically solved by physical activity. While the campaign needs a simple message, our audience must also understand Lupus in a more holistic way.

#1
Physical activity seems impossible for the severely fatigued,

#2
Many people with Lupus don't know how to get started.

#3
Physical activity is not a quick fix for people with Lupus.

Getting started with physical activity is a daunting task and people with Lupus don't yet have an easy-to-use reference to identify what types of physical activity would suit them.

Key outcomes of the workshop were as follows:

- Lupus Heroes was strongly supported, but will need to cover the whole spectrum, some very accessible, achieving apparently very simple things and heroes like Jeanette (who does a lot!).
- The idea of fostering exercise was also welcomed but it has to start slowly, so as not to discourage anyone, and then reach all levels in order to have suggestions for everyone, from tiny beginnings to people who run marathons.
- Kick lupus could be a symbol of different initiatives, a common word to link various things. We must understand who the audience is and adjust our message to the right groups.
- Kick lupus might be an entry to speak to students and young professionals differently rather than talking about something that is complicated and rare.
- We won't get money just because we have written Kick Lupus!, you need real events behind it, but it might initially attract attention.
- We should see how we can link the benefits of movement to lower health care costs and use that idea in lobbying.
- Kick Lupus! is also helping each other make the first steps. Having bigger/more mature organizations coach newer ones would be a great opportunity to explore.



The panel was concluded with a clear “Yes, we would like to have Kick Lupus! as a campaign that we could use in the next years...”

In the evening, we enjoyed a great tour of Würzburg by night, accompanying a traditionally dressed Night Watchman with his candle-lit lamp through the small streets of the old town, discovering many unexpected details of houses or churches and listening to his (funny) stories about the city's past.

Friday, September 30, 2016

Business session on Strategy

Workshop led by Alain Cornet – Secretariat – LUPUS EUROPE

LUPUS EUROPE's strategic plan will run for one more year, but the Board will start engaging between now and the next convention in order to draft the next 5-year plan so that it can be discussed when we meet in 2017. To prepare for this work, the board decided to gather input from participants. After an introduction from Kirsten Lerstrøm recapping the key strategic drivers of the 2009-2012 and the 2012-2017 Action plans, and a brief introduction to SWOT analysis by Alain Cornet, we started working in teams on identifying LUPUS EUROPE's key Strengths and Weaknesses, and then the external Opportunities and Threats we are or could be facing. The results

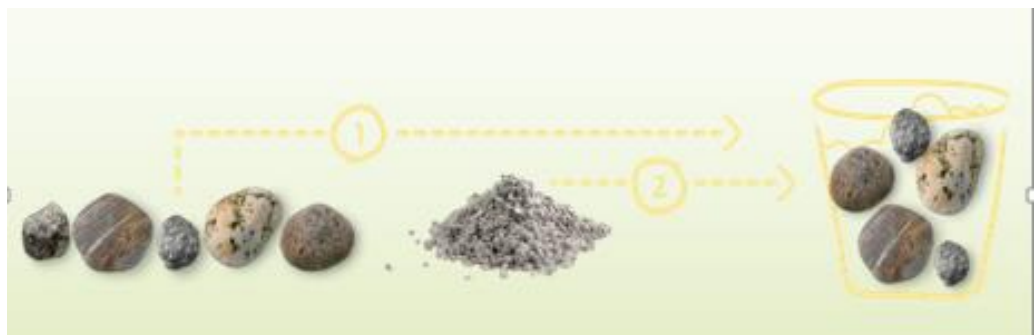


could be summarized as follows (numbers indicate how often similar ideas were repeated):

<u>Strengths:</u> The knowledge in our combined groups -8 LE representative size, covering Europe with one voice -6 Our networking and sharing -6 Our differences -5 The Positivity & Enthusiasm of strong women -5	<u>Weaknesses:</u> Lack of Resources (people and Money) -10 Language and distance barriers - 5 Disparity of national situations - 5 Members health constraints - 3
<u>Opportunities:</u> Involve partners (EPF, EULAR, WLF, ...) - 7 Role in developing new treatment - 6 Influencing EU & Pharma -4 Social Media - 3 Youth – 3 Partnership between members - 3	<u>Threats:</u> Financial (lack/reduction in resources) - 11 WLF - 3 Lupus getting off the agenda - 3 Brexit – 2

Note- For the sake of clarity, the table above regroups points highlighted by several groups or similar in nature. The board will include all results in its further work.

Alain then demonstrated the 5 Rock Concept: if you want to achieve what is really critical for you (the Rocks), it is important that you identify what that is, and ensure that that work is done first, and only afterwards include the less critical things (Stones), and the many minor tasks (Sand).



From this visual example, the workshop continued to identify what participants consider as the key Rocks for LUPUS EUROPE over the next 5 years. After sharing of each team's results, all participants "voted" for up to 4 items they would prioritize from all suggestions made.

Almost 90% of the voters expressed went to 10 "Top ideas" as follows:

One voice from Europe	19
Extending the website (library, interactive, link to local)	15
Unity in treatment in Europe + early Diagnosis	11
Finding new ways of funding + funding	10
Training & education	10
Support for individuals in member groups	7
Cross Border Health Care	6
Awareness	6
Influence on EU decisions	6
Gather knowledge of situation of lupus in Europe	6



Lupus in Germany – 30 years!

By Borgi Winkler-Rolfing, Chair, Lupus Germany



Lupus Germany was established 30 years ago as an independent organization of German Rheumatism Society, and today brings inspiration and support to people with lupus all over Germany. Borgi highlighted that studies show that group members are healthier thanks to earlier detection of flares and higher adherence to treatment, less depression and pain, better quality of life and taking more responsibility for their own health. That alone would be a good enough reason for their work.

Over the years, Lupus Germany has grown and now has 75 local groups nationwide, and some 3000 members. Lupus Germany provides training and support to its local groups, as well as Grieving Seminars and Communication Seminars. Its website provides up to date information, verified by doctors, and its Facebook page reliably answers questions raised, and announces events. Lupus Germany also provides flyers, books

and seminars on key topics related to lupus. It stays up-to-date by linking with the German Society for Rheumatology, EULAR, the Rheumatism Competencies Network, and its membership in the national Patient Council for Research and Studies.

Further, Lupus Germany has engaged in several research projects, including LULA (see below), studies on the impact of psychological stress, preservation of fertility, or the development of new medication. It has also identified that people with lupus have more tooth decay and periodontitis than others and they are now seeking better reimbursement of preventive dental care based on that research.

The key highlight of Lupus Germany's impact on research is LULA, a long-term study over 15 years with more than 500 patients still involved. It has systematically investigated more than 60 topics through scientifically validated questionnaires, but has also collected scientific data on those patients, year after year, creating the largest long-term lupus cohort in



Europe. The LULA data has been used by Lupus Germany in its advocacy work with the G-BA, the authority approving reimbursement of medication to be offered in Germany, enabling it to demonstrate that belimumab did drive additional benefits in lupus, and hence should be available.

A new “LULA2” cohort has now also been opened for enrollment to provide information on more recent patients. To further support research, Lupus Germany created the German Lupus Foundation, gathering funds for research.

LUPUS EUROPE Youth

By Jeanette Andersen – LUPUS EUROPE Trustee



The need to deal with specific youth issues (like pregnancy, education, work-life, new girl/boy-friend or socializing during the weekend) is obvious as lupus is often diagnosed when women are young. In addition, the progress of standards of care is such that newly diagnosed patients face a different situation than 20 years ago. The LUPUS EUROPE Youth (LEY) Facebook group created a year ago now has 62 members from 21 countries. Also youth groups have emerged in various countries and within the networks of other patient communities. We need and want more of those... To better understand the specific youth issues, LUPUS EUROPE is working on a concept for the next patient panel to focus on youth.

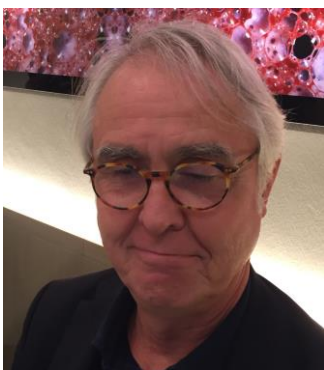
Following this introduction, participants engaged in discussions on youth, carrying over through lunch.... The key outcomes were as follows:

- There is an opportunity to better link the national youth groups and to cooperate with EPF-youth, YoungPARE, etc.. Each national group should appoint a contact person to stay in touch with LEY.
- Guidelines and support for starting a national youth group would help.
- The transition from pediatric care to regular “Adult” can be difficult, including the move from being taken care of by parents, to taking responsibility for your disease and treatment. Properly trained mentors (adult or peer) could help this process.
- Many ideas were offered on extra youth focused activities that LEY could drive, such as special youth events on WLD, a youth camp, training events for youth (starting a family, work life, studies, what to tell employer, co-workers, teachers) and for parents.
- LEY was encouraged to be active on social media: Youth Web site, blog, advertising for LEY on Facebook, Twitter and Instagram.



Members were asked to share this information with the young people (18-35 years) in their group and to direct them to Jeanette, who is ready to help where asked!

Systemic Lupus Erythematosus – HOW TO TREAT?



By Prof. Matthias Schneider, Policlinic & Hiller Research Unit of Rheumatology, Heinrich-Heine-University, Düsseldorf, Germany. LUPUS EUROPE Co-Opted Medical Advisor since 1991.

The first step of his presentation, Professor Matthias Schneider presented a table showing the different forms of studies and trials – what do the various terms actually refer to - from clinical study to clinical randomized study and more. This makes a difference when referring to the research and understanding what data sets are used.

Starting from a brief recap of the lupus “life cycle”, where genetic and epigenetic/environment factors precede the diagnosis, and organ manifestations and damage follow it,

Professor Schneider leads us to the BASIC of Lupus treatment: BASIC stands for Bone protection, Antimalarial, Sun protection, Immunization protection, and Cardiovascular risks: 5 measures that should be checked at each consultation. BASIC covers 90% of the treatment, but from there, the remaining 10% requires activating the BASIC+5.

The first element to add is the clinical assessment of the disease expression. Looking at elements such as Antiphospholipid-AB, and possible symptoms in the lungs, kidneys, joints, ... the assessment leads to an evaluation of the disease activity (mild, moderate or severe), which might lead to changes in indicated immunosuppression, and further adjacent therapy. To perform the assessment, doctors are helped by EULAR Standards of Care (SOC). For example, high proteinuria with active sediment should lead to a kidney biopsy that might raise the question of low-dose cyclophosphamide (CC) or mycophenelate mofetil (MMF), and perhaps adjusting levels of glucocorticoids... In turn, the question of required adjacent therapy for blood pressure or lipids would be raised.

mild (no risk of organ failure)	moderate (risk of organ failure)	severe (Life threatening)
ARTHRALGIAS	POLYARTHRITIS	
	GLOMERULONEPHRITIS	RAPID PROGRESSIVE GLOMERULONEPHRITIS
MILD HEADACHES	ENCEPHALOPATHIA	CEREBRALE VASCULITIS
	THROMBOCYTOPENIA (15-30K)	LEUKOZYGES < 1K
	PNEUMONITIS	PULMONARY BLEEDING
EXERTIONAL DYSPNOEA, NAD	MYOCARDITIS	PERICARDIAL TAMPONDE
FEVER (MAX. 38,5°C)		



Next, the assessment will need to carefully consider symptoms of activity and possible damage, but also whether those symptoms could be non-lupus related. Fever is a classical example, where treatment would differ greatly depending on whether it's lupus related (increase immunosuppressant), or related to an infection (do not increase immunosuppressant).

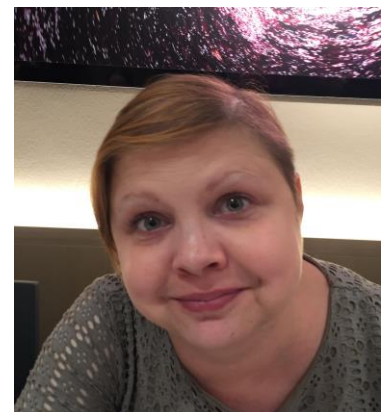
The 3rd element will integrate patient reported outcomes (PRO), targeting control of the disease activity, minimizing comorbidities and drug toxicity, ensuring long-term survival, preventing organ damage, but also optimizing health-related quality-of-life.

BASIC+4 will be to use a lupus maintenance treatment that aims for the lowest glucocorticoid dosage needed to control disease, if possible completely withdrawing glucocorticoids.

This then leads us to BASIC+5, aiming for remission, which Dr Schneider defines as no active organ manifestation (SLE/APS), a validated disease activity score ≤ 1 , no flare, glucocorticoids ≤ 5 mg and a Health related Quality of life(HRQoL) $\geq 90\%$ of normal population.

To treat to remission, we need

- (i) effective disease control to get no active organ manifestation,
- (ii) preventive interventions to avoid flares,
- (iii) rapidly acting drugs other than Glucocorticoids, and
- (iv) an interdisciplinary team to help achieve almost normal HRQoL.



LUPUS EUROPE has taken active part in developing new definitions in lupus. Kirsten represented us in the definition of Treat to Target (T2T), that lead straight to definition of remission in lupus – DORIS, where Cindy Coney representing Lupus Foundation of America, Petra Balážová represented the EULAR trained patient research partner, Bernadette van Leeuw and Kirsten Lerstrøm representing LUPUS EUROPE took part.

(The full transcript of Matthias's conference will be soon available to members on LUPUS-EUROPE.org members section)

After Prof. Schneider's presentation, we gathered for a guided tour of Würzburg "Residenz", and its gardens, followed by a wine tasting and dinner in an old but still active wine cellar of the city center.



Saturday, October 1, 2016

On Saturday, it was suggested that participants share their experience on some aspects of living with lupus. These testimonials have been video-recorded by Mikkel Pedersen. The material appears very rich, and the Board of Trustees will consider the best way to use it.

What is lupus?

By Professor Martin Aringer, Medizinische Klinik und Poliklinik III, Universitätsklinikum Carl Gustav Carus, Die Dresdner Universität, Germany

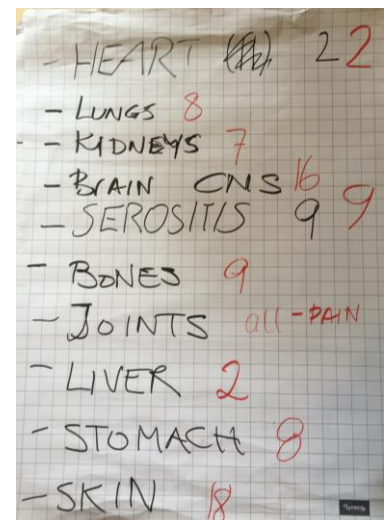


Professor Aringer led us through a deep understanding of diagnosing lupus. Understanding what biological signs indicate lupus requires identifying markers that are not only highly sensitive (i.e. they are present in most people with lupus), but also highly specific (i.e. when they are present, it is very likely that it is lupus, not another disease). ANA for example, is highly sensitive, since more than 98% of SLE patients are ANA positive, but not specific, as ANA is found in all connective tissue diseases (Sjogren's,...), thyroiditis, rheumatoid arthritis, virus infections... on the other hand, Anti-Sm is low sensitivity (less than 1/3 SLE patients is anti-Sm positive), but very specific, as it is very rare that Anti-Sm positive patients do

not have SLE.

Similarly, identifying lupus by its symptoms can be challenging as symptoms can come early or late depending on which organ is involved. For example, symptoms of lupus nephritis will come rather late (edema, headache, hypertension) after organ damage has started, while fatigue, or joint pain may come early but lack specificity.

Involving everyone in an interactive session, Prof. Aringer highlighted the vast area of organs affected and then led us to contemplate how the specific organ manifestations link to different biological markers in the blood. Classification of lupus can be done by looking at the combination of markers



and organ symptoms, but each set has a defined sensitivity and specificity.

By moving from the 1997 ACR-endorsed (American College of Rheumatology) Criteria for SLE, where 4 out of 11 clinical manifestations would lead to a SLE diagnosis, to the SLICC (Systemic Lupus International Collaborating Clinics) Criteria for SLE - defined criteria, sensitivity increased from 83 to 97, but specificity decreased from 96 to 84. As a result, it is important to find one set that is both sensitive and specific.

Dr Aringer explained why fatigue was not retained as a lupus diagnosis symptom: the symptom is frequent in SLE, but equally or more in the “mimickers” group. This lack of specificity could lead to diagnosis and treatment errors.

At this point, a number of additional criteria are being evaluated to add to the list so as to increase specificity without reducing sensitivity. Professor Aringer’s suggestion is that defining SLE would require first to have an entry criterion that is highly sensitive, like ANA, then a set of confirmation criteria that are highly specific, like the involvement of two organs or one organ and an independent antibody.

The project is in process and is moving into the second phase. LUPUS EUROPE has been invited as observers to annual workshop meetings on this topic at EULAR the past two years.



Genetics of Lupus and the PRECISEADS Project

By Professor Marta Alarcon-Requielme, Karolinska Institutet, GENYO. Center for Genomics and Oncological Research Pfizer-University of Granada. Head of PRECISEADS - IMI/JU project



Lupus mainly affects women, so many studies have been done on hormones and the X chromosome. Some extra research needs to be done on other factors such as the anemia created by women’s periods, or other female specific conditions, but the current work of PRECISEADS focuses on genetic structures.

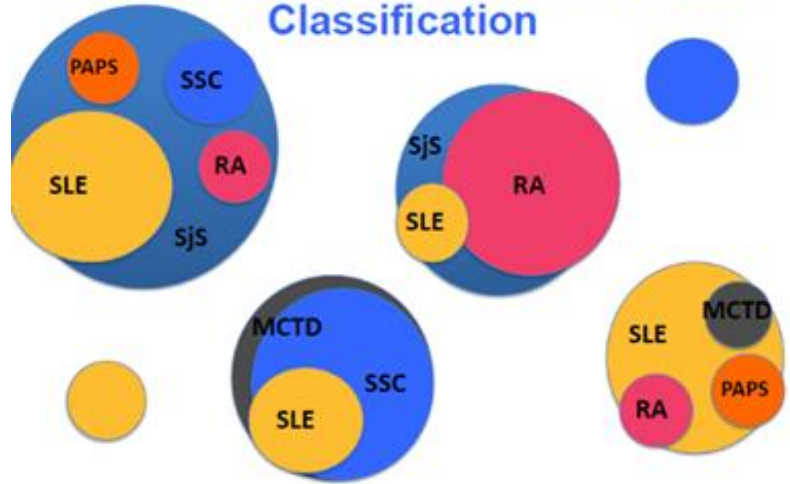
Prof. Alarcon explained how DNA essentially works and how it expresses itself in proteins, but also needs to be regulated by proteins and the environment around it. Health or disease may depend on genetic adaptation and our response to the environment.

Disease can occur with drastic environmental changes (such as an excess protein diet or examples such as how obesity has been linked to type 2 diabetes), but also situations where a particular genotype is both necessary and sufficient for the disease to exist, regardless of the environment (e.g. hemophilia). Most often two or more genes have to exist in a specific expression for a disease to occur, and they have smaller or greater contributions vs. environmental factors.

It is the combination of genetic and environmental factors that, in lupus, creates an altered response of the immune system to the environment (interferon signature). Early studies show that there could be 7 different types of patients where regulation of gene expression is different during disease activity, but much work is still needed to validate this.

The PRECISESADS (www.precisesads.eu) project is a Pan-European project that, starting from the knowledge that Systemic Autoimmune Diseases (SADs) have partly shared genetics, shared biomarkers and signatures, considers if we could reclassify those diseases in a new way, based on a New Molecular Classification. If this proves to be correct, we could then have new classifications that would group some types of lupus, for example with some type of RA, and some type of systemic sclerosis under one “disease” expressed in different ways, and other types of

We expect to make a New Molecular Classification



lupus grouped with other types of Auto-Immune (AI) diseases under another “disease group”. This in turn could lead to different treatments, based on different genetic origins. The project will involve several thousands of patients with various autoimmune diseases, with several universities around Europe engaged in this 5-year project (which we hope will be prolonged).

Blanca Rubio is the LUPUS EUROPE representative on the project’s Ethics Committee, until the project final date in 2018.

Registries and LULA

By Prof. Matthias Schneider, Policlinic & Hiller Research Unit of Rheumatology Heinrich-Heine-University, Düsseldorf, Germany. LUPUS EUROPE co-opted Medical Advisor since 1991.

Prof. Schneider showed that from case reports to clinical randomized testing reports, various data sources are available with different scales and contents. Some of these reports will only show correlations, but the understanding of causality vs. inter-dependency between elements is critical. As an example, people with lupus that work show lower fatigue, but is it because of lower fatigue that they work, or because they work that they have lower fatigue? In depression, helplessness is the biggest causal factor of fatigue... Cohorts analysis is one way to understand such elements that individual case studies or clinical testing cannot



explain: By following patients over time, the chronology of measures shows causes of mortality, predictors of damage, etc. But cohorts require significant numbers of patients enrolled and staying to trigger valuable insights, as well as consistent unbiased data and a proper reference group.



The UNITED project attempted to bring together all the data available from national/regional cohorts, but unfortunately did not obtain the required funding. LUPUS EUROPE was an active part of the consortium. Yet, the potential of having data on “all” patients around Europe is incredible. We could identify connections that are unsuspected today. Some national registries are incredibly complete and allow much analysis, but statistically relevant data requires Pan-European or global information when you want to work on specific lupus manifestations.

Professor Schneider shares his hope and confidence that a Lupus Registry will one day exist. It will be a huge amount of work, but simply has to happen. The European Lupus Society, that has just been created, will build a community of researchers interested in SLE, attract younger physicians, promote and coordinate research and conferences, and encourage the awareness and development of the discipline with regards to prevention, treatment and management, supporting research projects and clinical trials.

LUPUS EUROPE will naturally be part in this new initiative.

Professor Schneider then showed us some (still confidential) data from the LULA cohort, showing for example that for people with lupus, social interaction is a key driver of quality of life (if you are married, your QoL is better over time!). He concludes, stressing that Quality of Data reported by patients has been shown to be as reliable as what we get from doctors (and tests) if it is properly collected.



MASTERPLANS – innovative and extraordinaire UK project

By Yvonne Norton, Vice-Chair LUPUS UK



Maximising Sle Therapeutic Potential, Application of Novel and Stratified approaches - MASTERPLANS)

Lupus is complicated, treatment is complicated!

MASTERPLANS is a clinical study (not a clinical trial) that aims at understanding if specific patterns of genes and chemicals in blood, urine, skin and kidneys can predict who will do well / not so well on specific drugs, in order to replace the current “trial & error” method that prevails in lupus treatment. It is a 5 year project with more than £10M in public funding.

Each patient presents a unique fingerprint of organs involved, severity and response to therapy. These differences are paralleled by a range of underlying genetic and immune function abnormalities. While only half of patients respond well to each drug, certain groups respond better than others...the goal is therefore to identify and specify groups of patients that respond well to particular therapies

As a minimum 240 patients will enroll in the project.

The project involves 6 work-streams: Some work on analysis of specific patterns (Genetics, Skin, Kidney and Blood/Urine), another will collate the data from all work-streams (Statistics), and the last will look at cost impacts (Health Economics). This is a large project, involving 16 Hospital Trusts, and works with a high level of Public / Patient Involvement (PPI). Patients provide input into the project from end-to-end, sit on each committee, and comment on study design.

SLE is probably a disease with different subsets, which may do very well with targeted therapy. We need to develop more precise ways to identify who fits which therapy early on. We look forward to the project results.



World Lupus Federation

By Kirsi Myllys, Treasurer of LUPUS EUROPE



Kirsi highlighted the status of World Lupus Federation: Last year in Vienna, lupus world leaders concluded that we need a global organization to coordinate global advocacy and awareness, earlier lupus detection and treatment, and proper access to care and support services.

The World Lupus Federation (WLF) delivered the first results by organizing a global WLD campaign last May, and launching the new website, but much remains to be done: aligning a strategic plan, identifying the needs and priorities of members, setting up an Executive Advisory Committee. The goal is to have a fully operational WLF by 2018.

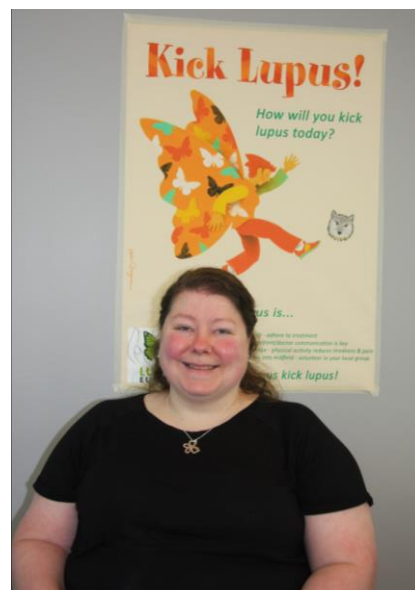
But the road so far has also been a bit bumpy: working on the one hand with professional vs. volunteers in different geographical areas creates issues of speed and means. The need to deliver results to justify funding received also created a bias of Action vs. Consensus, a difficult balance to meet. And the recent call for membership created concerns that the base selected to define who can or not be a member is not in line with initial expectations. Kirsten and Kirsi will continue to carry LUPUS EUROPE and its members' voice to the WLF steering committee.

World Lupus Day (WLD)

By Jeanette Andersen, Trustee LUPUS EUROPE

Jeanette guided us through a discussion of the 3 options we have for World Lupus Day: (a) Follow the World Lupus Federation theme and guidelines, (b) Create a common European theme, distinct from WLF, or (c) Each follow their own separate national themes.

After productive discussions in the team, 13 votes were in favor of following the WLF theme, 4 would prefer a European campaign, but most recognized that while they might need to add local tweaks, and serve national interest, they would not have resources to do it alone.





Recent developments in Lupus Italy

By Daniela Rava and Augusta Canzone, Lupus Italy delegate and Chair

Daniela and Augusta highlight key results of the survey Italy conducted in 2015 on Quality of Life. It concluded that healthcare models do not meet patients' complex needs, affecting quality of life and patient-physician relationship. Over 80% reported bone and joint pain, with working life most affected, and stress being one of the most important factors jeopardizing illness trend.

A new survey is now planned in 2017, focusing on the importance of stress in everyday life, the difficulties and access to treatment, and the communication gap between doctor and patient. Another project in 2017 will look at early stressful events as predictors of SLE onset or progress, and the role of psychological assistance in managing this.



Recent developments in Lupus Greece

By Anna Karliampa, Lupus Greece delegate

There is no lupus specific patient organization in Greece, but Lupus Greece is part of ELEANA, the Hellenic League Against Rheumatism. ELEANA offers a helpline, which also tracks linkage between rheumatic diseases and mental health. The line, available nationwide, receives 600 calls each year, lasting an average of 20 minutes. Many of the callers come from remote areas of the country, further stressing the importance of such a line available to all. In Anna's region, they also walked for lupus earlier this month, a small distance of just 1.5 km, but making the point that no matter how little you can do, exercise will help.

Recent developments in Lupus Sweden

By Sara Badreh, Lupus Sweden delegate

Sara Badreh then brought perspective from Sweden, where a lupus specific grouping will be created as a "district" of the Swedish Rheumatism Association. This group will have its own activities specialised and adjusted for SLE patients, be in charge of arranging the WLD, be a first contact to those newly diagnosed with SLE, raise lupus awareness, and bring the voice of SLE members to the broader Rheumatism Association.



Neovacs and Thellie

By Anne Charlet, LUPUS EUROPE Vice Chair and Sara Badreh, Lupus Sweden delegate

Sara and Anne then continue with a brief explanation of the Neovacs vaccine project. In essence, as Interferon alfa intervention (IFN α) is thought to play a key role in the causation and development of flares in lupus (it doesn't develop lupus if you don't have the genetic default for it) for some patients, by stimulating the immune system, Neovacs developed a system to trigger the body to attack IFN α so that it will not exacerbate the immune defense system, hence preventing lupus from becoming active.

Anne goes on with a presentation of Thellie as a crowdfunding platform for the support of specific projects in the lupus area (www.thellie.org). The name comes from combining the names of the two persons central to the creation of the project – Julie and Thelma. See more on their web site.

Skype connection with Andreas

With Andreas Panteli, Member of Lupus Cyprus, Lupus Switzerland and Lupus UK, living in South Africa, and training to run New York Marathon



After the coffee break, we enjoyed an inspiring Skype connection with Andreas Panteli. Andreas has been training to run the New York Marathon, running each week for a different member country of LUPUS EUROPE. He has overcome the many obstacles by keeping each of us in mind, he said. As he knows the end of the marathon will be the toughest part, his

plan is to run each of the last 24 km for a specific country. Andreas is a true Lupus Hero, and we will all be with him on the 6th of November.

Recent developments in Lupus Portugal

By Rita Mendez and Ines Simoes, Lupus Portugal delegates

Lupus Portugal will celebrate its 25 year anniversary next year. Because many people do not have access to treatment in the countryside, they need to come to Lisbon for treatment. Lupus Portugal maintains a house in Lisbon where those people can stay for the duration of their treatment. Last year, they benefitted from a 20,000€ grant to renovate the house. This year, for the first time, they organized a sponsored “1st Lupus Running”. The objective was to attract some awareness on lupus and the AdLUPUS organization. Their structural issue, like that of many members, is the lack of resources, both human and financial. They would very much appreciate any idea and support we can contribute to help them attract more volunteers and better raise funds.



Engagement and dissemination

Workshop conducted by Kirsi Myllys (Treasurer, LUPUS EUROPE) and Katharine Wheeler (Secretary, LUPUS EUROPE)

From a current reality of being all very active, but acting separately, we would like to identify how LUPUS EUROPE can help us to be more engaged together, with more interactions. Participants split into 3 groups to discuss the matter and then shared the outcomes.

The following came back as key highlights:

- The website shows as a key area of intervention, mentioned by all. Using Facebook or blog more extensively could help.
- Also, a repeated request for reports from events: the board does many things, there is little information coming back as to what was done and what was learned.
- The need for action could be further stressed: in the emails text, making the emails easier to read, highlighting what is expected ahead of convention.
- Having more people participate in conventions, but also day-to-day.
- On surveys and information about response, letting people know what the outcomes or interim situations are.
- Creating a template highlighting what projects or info we are interested in receiving from members for sharing.
- 1-pagers on our partners and key events: who are there, why it is relevant for us, that would help newcomers on board.



In the evening we joined 70 members from Lupus Germany for the Gala Dinner celebrating the 30th anniversary of the German Lupus Group. We had songs, magic shows and inspirational speeches. Thank you Lupus Germany for hosting this very special LUPUS EUROPE Convention 20



Sunday, October 2, 2016
Minutes of Council meeting of LUPUS EUROPE
Held at GHOTEL, Wurzburg on October 2, 2016, 09.15-11.45

1. Kirsten Lerstrøm, Chair of LUPUS EUROPE opens the session at 09:15, thanking Borgi and Simone for hosting LUPUS EUROPE Convention 2016 and the great party they offered yesterday for the 30-year anniversary of LUPUS Germany, then going through the Meeting Agenda. Calling of Council Meeting was conducted in due time. No additions to agenda proposed. Note taken by LUPUS EUROPE Secretariat, Alain Cornet.
2. Katharine Wheler, Secretary of LUPUS EUROPE, verifies that we have quorum. Attendants are Belgium (FR), Denmark, Finland, France (LF), Germany, Greece, Italy, Lithuania, The Netherlands, Norway, Portugal, Slovakia, Spain, Sweden, and United Kingdom. With 15 fully paid-up voting members and the Board of Trustees, we do have quorum. Each voting member, whose membership fee has been paid, receives a voting sheet and a flag. The flag is used to express a vote. An observer bureau is composed of Peter Norton, Georgios Pateras and Alain Cornet.
3. Chair Kirsten Lerstrøm then reports on past year's activities.
 - The 2015 convention was a highlight, with very positive appreciations, but the combination with ICL made it a bit overwhelming, and members asked for more time just amongst ourselves. We learned from this when building this convention. At the same time, this was a unique opportunity to meet and exchange with friends from all around the world.
 - Kirsten thanks Trustees, Secretariat and co-opts for the great work done over the past year. Key activities of this year included preparation of Convention 2016, World Lupus Day together with WLF, a focus on Youth with the launch of a dedicated Facebook group, launching the Survey on Sun Protection, the second Patient Panel and substantial work with the World Lupus Federation. We also fostered the submission of abstracts for European Lupus Meeting, leading to 2 oral presentations and 3 posters included in the scientific programs. This is major progress, as patients are now included in the scientific program.
 - LUPUS EUROPE also attended many events, from where key highlights were shared and tweeted. Blanca will issue a report soon about EULAR PARE conference. Four of us attended EULAR in London, with a report soon to come. European Lupus Meeting next week, EUPATI and Eye4Pharma are other highlights. We were also engaged in many projects, including DORIS (definition of remission in SLE), the Patient Panel on Treatment, PRECISEADS, the EULAR Study group and ACR/EULAR reclassification, as well as various applications and consortiums. Also, Anne presented at IAPO's Global Patients Congress on the experience of Patient Panels and Campaigns. We provided our members with information on the EUPATI Toolbox and enrolled one member as an expert trainee in EUPATI, reviewed and contributed to layman's versions of recommendations thanks to our Patient Research Partners, provided input to the SmiLE-Survey, actively participated in EPF meetings and work groups, and supported Andreas Panteli in his run for Lupus! Next, another active year for LUPUS EUROPE.
4. Kirsi Myllys, Treasurer, then reports on Financials:
 - Our accounts for 2015 were submitted on time to the charity commission, with a clean review from our auditors. As a reminder, while we submit our accounts in UK pounds (£), most of our activities and currency holdings are in Euros (€). In our reporting year ending October 31, 2015, we generated income of £62,322, and spent £77,018. When including the loss on exchange due to the strengthening of the pound during 2015, we faced a significant net loss of almost £20,000, resulting in lower-year-end cash balance on account of £57,218 versus £76,559 at the beginning of the year. This loss is

attributable to the fact that a committed sponsor payment of 20,000 Euros arrived few days after the closure of our books, meaning it could not be included as we follow a cash-based accounting method.

- Kirsi then details our income, largely coming from Grants (62k€), Convention income (9k€) and London marathon (5k€), then highlighted expenses where the convention (39k€) and secretariat (37k€) are the leading items with Board meetings, external focus and projects much smaller around 6k€ each. She closes the review of 2015 by highlighting that at year-end, more than 2/3rd of our funds were “unrestricted”.
- Turning to the current year, which will only end on October 31, 2016, we forecast our income will reach 65.3k€, and expenses only 57k€. This, together with an expected exchange gain of 8k€ should give us a substantially positive result in excess of 16K€€. The increased income is thanks to additional grants (other income stable comparable to a year ago). The spending decrease is due to a change in secretariat, partly offset by project costs from the Patient Panel. Kirsi concludes that the most significant uncertainties remaining this year relate to the time at which the promised UCB grant will reach our account, and to the exchange rate from Euro to Pound.

5. The Treasurer seeks approval from the Council to:

- a. Delegate approval of the accounts to the board, as the next council will be after the deadline for submission to the Charities Commission.
- b. Approve the appointment of JMS accountants as Auditors in case the accounting method remains on cash base.
- c. Delegate to the board the decision of changing accounting method, should the situation justify it, and the appointment of other auditors in that case.
- d. Approve the continuation of Membership fees at the current level of 200€ for large groups, and 100€ for small groups and associates (Yvonne Norton from UK flags that associates are unlikely to pay the fee, which is acknowledged).

6. The council approves the financial report and proposed decisions at unanimity.

7. The Secretary, Katharine Wheeler, then announces that Blanca Rubio and Kirsi Myllys mandates are expiring. She thanks Blanca Rubio for years of service on the board of trustees. Her skills in moderating debates have been particularly appreciated. The Board also extends particular thanks to Simone Pretis and Borgi Winkler-Rolfing for the hosting of the convention, as well as to Petra for her tweeting and posting on FB all throughout the convention and for her active engagement in getting us to exercise and Mikkel for his handling of so many support tasks during the convention. Katharine then explains that Kirsi Myllys, whose mandate is also expiring stands for reelection, and that Sara Badreh from Sweden is a new candidate for a trustee position. The mandates will expire at the 2019 convention. Each appointed member representative (15) and Trustee (not representing a country, i.e. 4) is asked to express his/her vote using the distributed ballots. Ballots are collected by Peter Norton and Alain Cornet, and the Council breaks at 10:45 for coffee.

8. After the break, Michael Majchrzak joins us by skype from Poland. For years, he has been following LUPUS EUROPE and is now trying to establish a support group in Poland. There is clearly a lack of awareness and training, including at the doctor level. While the group only started in May, it already has a fairly active Facebook page and has organized its first events.

9. Peter Norton then announces the results of the elections. Of the 19 votes expressed, 1 is invalid. Kirsi Myllys is re-elected unanimously. Sara Badreh is elected unanimously less one abstention.

10. Kirsten Lerstrøm then covers LUPUS EUROPE priorities for 2017. These will still follow the strategic plan 2012-2017, and the key rocks will be:

- On Strategic driver 1, PEOPLE WITH LUPUS in Europe participate in, and benefit from, lupus research, we will focus on (1) establishing a task force on research and clinical trials that will define how LUPUS EUROPE can best grow patient knowledge to foster participation and deliver quality input from the start in research and (2) prepare 2017/18 patient panel on youth.
 - On Strategic driver 2, Member organizations are enthusiastic and empowered, we will focus on (1) reinvigorating silent groups and fostering new ones, (2) making Convention Pisa 2017 the best you ever experienced, (3) actively engaging in shaping a winning World Lupus Federation, and (4) creating synergies through WLD and campaigns.
 - On Strategic driver 3, LUPUS EUROPE is heard and acting, our focus will go to (1) preparing LUPUS EUROPE's 2018-2022 strategic plan for finalisation at next convention, (2) reviewing the impact of Brexit and recommending an action plan (or confirm status quo), (3) defining HOW we get the lupus voice to EU level, and (4) strengthening succession plans.
11. We will continue to engage externally, with involvement in study groups, task forces, and research, contribute to results, inform partners and disseminate outcomes. Of particular importance in this area will be the EULAR study group on SLE and its offshoots, the SmiLE sunblock survey, the EPF working groups, the autoimmunity network, and the WLF. We will also ensure active participation in congresses and forums, where we can represent our members, share learning, and learn from others. These include EULAR, ICL 2017, PARE, ELM, EPF, IAPO and EUPATI.
 12. Kirsten then highlights that any person interested in a more active participation is welcome! Depending on interests and time available, we can work out how to best involve anyone interested. She then concludes by announcing next year's convention in Pisa, Italy, from November 15 to November 19, 2017.
 13. The Council session is closed at 11:45



Pictures and illustrations

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