



## UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

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### 2016 CONVENTION REPORT, VIENNA

#### World Lupus Congress Patients' Program

Whether in Europe or in Indonesia the key activities for the lupus groups are awareness and improving access to competent care and treatment.

Meeting up at the International Congress for Lupus is fantastic and to connect with amazing people from other networks, countries and patient situations is great and most rewarding.

This is also the reason why the organizations do all they can to make this happen and raise funds to cover the attendance. This is an investment for the organization and will most likely take a huge part of the general activity budget, so it will have to yield result.



In other years, the patients' forum of the World Lupus Congress was a program held in parallel to the scientific sessions, in the national language. This was not optimal, as attending the scientific sessions and activities are the main reasons for registering for the congress. Delegates registered for the congress benefit from sharing experiences and exchanging knowledge and information for use in their national groups.

In order to promote this rich exchange of information and experience, LUPUS EUROPE decided this year to organize a patients' program around the World Lupus Congress in Vienna, with a focus on capacity building for lupus leaders and offering the chance to discuss the current issues key for us both nationally as well as globally.

The patients program agenda:

**Wednesday, September 2<sup>nd</sup>**

**Round Table Disseminating Key Results from recent Projects and Recommendations**

Maria Theresian Apartment 1, 12-14.30, Invitations only

**Friday, September 4<sup>th</sup>**

**Lupus World Engaged!**

Gartensaal, 9-12.30, All patients and medical panel/project leaders have priority access

**Saturday, September 5<sup>th</sup>**

**Lupus Patient Leader Summit – Meet the World of Lupus**

Gartensaal, 9-16.45, Patients registered to attend have priority access

**Sunday, September 6<sup>th</sup>**

**World regional meetings - LUPUS EUROPE Council and Convention**

Hotel Leonardo Vienna, Matrosengasse 6-8, 1060 Vienna, 9-16,  
LUPUS EUROPE members and special guests only

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### Wednesday, September 2nd 2015 – Round Table on Disseminating Key Results from recent Projects and Recommendations

Prior to the official LUPUS EUROPE convention opening, LUPUS EUROPE organized a round table session on, “Dissemination of Key Results from recent Projects and Recommendations”. The reason for staging this event is that we have some important results from studies, international initiatives and newly agreed recommendations which are important to share with people living with the disease in Europe. In all about 25 people attended the meeting with patients from Canada, Europe, Africa and Asia, together with representatives from industry: GSK, UCB and AbbVie. The discussion was lively and we gained valuable input and insight to the importance of sharing results.

#### Why set targets for lupus treatment? – what was the result of T2T and status on defining what is remission in lupus By Professor Marta Mosca MD PhD, Pisa University, Italy

Professor Marta Mosca presented on how it is possible to set targets for such a complex and complicated disease as lupus. The four overarching principles and 11 specific recommendations received high agreement among the international faculty, yet the question on how to define remission for lupus was the basis for a whole new initiative. Definition Of Remission in SLE (DORIS) was a project launched in 2014 with representation from a wide global lupus specialist group, nephrologist, dermatologist, immunologists, health care professionals and four patients: Cindy Coney from Florida, Petra Bedranova from Slovakia, Bernadette van Leeuw from Belgium and Kirsten Lerstrøm, Chair of LUPUS EUROPE and also patient representative in the T2T project.

#### EULAR Recommendations for Women’s Health in SLE/APS by Professor Angela Tincani, MD, Brescia General Hospital, and University of Brescia

Professor Angela Tincani led this project, where Francesca Marchiori (IT) and Judith King (UK) represented lupus patients. Professor Tincani gave a thorough presentation of the recommendations: principles and key issues (see notes on this by F Marchiori, Friday’s session).



During the discussion one particular issue, proper counseling by the treating physician on pregnancy was discussed, but this most likely because we had quite a few young women in the audience! A strong indication of the necessity of diffusion of these recommendations.

After the Q&A session, Nuria Zúñiga, LUPUS EUROPE co-opted Trustee for Social Media, went through the different channels of dissemination and the usefulness and effects of each one. She presented about how to make things happen, through discovering her own voice because of lupus. And using this voice as Nuria, we will conquer the world! Together we are stronger, all the

while maintaining our own integrity as a person and a group.

For the next steps we received many good ideas and immediate identification of the most easily achieved immediate goals. In particular, we learned that EULAR has decided to have a layman’s version of the EULAR Recommendations made, so we just have to push for having the *lupus* recommendations made available for the groups as soon as possible.

This was a new way of staging venue, subject and input for an in-depth discussion on key and most relevant issues among lupus stakeholders. Not the last time!

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### Friday September 4th, 2015 – Hofburg Congress Centre – LUPUS WORLD ENGAGED!

Anne Charlet, Secretary of LUPUS EUROPE opened the session at 09:00 welcoming all attendants for this First Patient-focused meeting and opening the first session, focused on “Engagement”.

#### Experience from EULAR task force on Recommendations, by Francesca Machiori:

Trained by Eular as a Patient Partner in Research (PPR), Francesca participated in the project “*Recommendations for the management of family planning, assisted reproduction, gestation, delivery and menopause in patients with Systemic Lupus Erythematosus and Antiphospholipid Syndrome*”. This work was done between July 2014 and June 2015. The team, composed exclusively of volunteers among rheumatologists, immunologists, obstetricians, nurses and patients, from all over Europe. The result is that we now will have (soon to be published) evidence-based recommendations developed by expert consensus on family planning, assisted reproduction, pregnancy and menopause for SLE and APS patients.

The key recommended principles are (a) that doctors should embrace, *not warn against* pregnancy, after consideration of individual risks, and (b) that decisions regarding family planning are a patient decision under counselling of health professionals. Discussions about family planning should take place so that patients are properly informed, taking into account that fertility decreases with age.



The health care professional’s advice should cover contraceptive measures, assisted procreation, and methods to preserve fertility. With regards to fertility, a special focus in the discussions went about assessment of disease activity and therapies to prevent/manage SLE flares during pregnancy. Another discussion considered menopause, including hormone replacement therapy, guidelines for screening on cancer based on SLE specific risk factors, and the recommendation to take HPV immunization.

Francesca’s perspective from participating in this project is that we are not too old to learn. At EULAR we are part of a network (PARE network of national and European patient organizations for RMD) and trained to handle these projects: As patients, we have a valuable opinion and experience. We might not fully understand everything immediately, but people, including doctors, are there to

answer questions, and it is absolutely fine to ask! But most importantly, as we represent patients, our opinion is important and listened to.

Because we represent patients, part of our role is also to disseminate what is said, ensuring “translation” for the general public, so that all people with lupus can understand what concerns them. This includes having a translation in local language. One of the roles of the PRP should be to translate into his/her own language.

From a methodology point of view, everyone from the very broad and diverse team was invited to share all his questions in writing. There were so many questions... and in the end, everyone was also asked if they agreed with the outcome, so the team really remained united.

#### Experience from International Study Groups initiatives on T2T and DORIS, by Kirsten Lerstrøm

Kirsten started by sharing her experience as part of the Treat to Target (T2T) study group. The first meeting considered the complexity of measurement of disease activity, and discussed whether we should or not go with a project of treat to target. The team concluded that it should be pursued because research shows better outcomes for patients when there is a specified treatment target: research has already resulted in successfully applying T2T principles for Diabetes, Hypertension and RA. The T2T project started with 18 people in May 2012, but over time the team grew truly multidisciplinary to 36 people including patients. The meetings used the Delphi method: you start from formulating

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research questions to be validated by literature and research, then people vote on what they think is most important, and the team moves forward with those topics.

While T2T goals can be multiple (control of disease activity, reduction of damage or quality of life), all T2T plans should be carried out according to basic principles: (a) *Shared* decision (patient and physician), (b) focus on *Long term* survival, prevention of organ damage, optimizing quality of Life, (c) the approach should be *Multidisciplinary*, taking the *whole person* into account, and (d) *Regular* long term monitoring and review of therapy, as opposed to only managing flares.

But at some point, the team arrived at the complicated question of defining Remission. For this purpose, another team was assembled in 2014, DORIS (Definition Of Remission In SLE), to develop potential definitions of remission for use in practice and clinical trials. This definition could also impact health policy decisions, so it is important to carefully define when it is that your disease activity is so low that you can be considered in remission, because the treatment applied effectively controls activity. Two main strands of a definition have been made: “off treatment”, or “R-off” (perhaps allowing chronic, basic treatment) or “on treatment” or “R-on” (allowing treatment other than hydroxychloroquine and steroids and at what minimum).

An important question is whether you can have remission “on treatment”. Usually remission implies that you are off treatment, but for lupus patients, it was judged relevant to also define a remission on treatment as less than 3% of Lupus patients will go off treatment for more than 3 years.

Various definitions are tested using existing data sets from all over the world, with the first results shared in August, but more work is required. The next step is to test the 16 definition elements following the two strands R-on/R-off.

In this project, the patient representative focus is to make sure that the definition is actually understandable and operable, not just technically, but also to make sure patients understand it and that it can be used in T2T.

Kirsten’s opinion is that remission requires “off treatment”, even if indeed remission does not mean you are cured. This is because many medications still have side effects (so a remission “on treatment” would carry those), difficulty in distinguishing this particular condition with reactions to various treatments of other symptoms) and because being in remission would potentially have administrative impacts (reimbursement, ...). Voices in the room suggested that if the treatment is acceptable with limited side effects, then remission is a lower disease activity that results in a proper social/quality of life. But quality of life is not chosen as a measure in this context.



### Experience from the Innovative Medicines Initiative (IMI), by Blanca Rubio

Blanca participated in the Ethics Committee of IMI, in the scope of the PRECISEADS project. PRECISEADS is a European collaborative project within the Innovative Medicines Initiative (IMI). It involves 23 research centres and 5 companies from 12 European countries, and benefits from huge EU funding, with a total budget of 22M Euros over 6 years. The objective is to understand the origin of autoimmune diseases, and why people with a same diagnosis (like “lupus”), respond to some medications and others not. This understanding would drive a better map of treatment for patients. The option selected is to classify diseases according to biomarkers or other indicators. The scope is not just lupus, but also other autoimmune diseases, where today there is little sharing across disease specialty centres.

There is growing evidence that many of these conditions may be incorrectly classified. Data collected on the molecular causes of their disease and clinical symptoms of 2 500 people with autoimmune diseases, will be used to build a new classification of Systemic Autoimmune diseases based on meaningful clinical biomarkers, that will allow doctors to offer patients more personalised treatments at an earlier stage.

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Similarly, while new biological treatments are being developed for SLE, it is not always clear which lupus patient will respond to which treatment, leading to problems in determining the usefulness of drugs in clinical trials, possibly because the results are good for some patients, but have no effect on others, blurring the statistics. For many years, no drug development has come to maturity. We need new medication, and this new classification could really help.

The ethics committee in which Blanca participates originates from an EU requirement. It contains as a minimum a lawyer, a social worker and a patient representative. They operate independently of the project, and control / analyze the personal aspects of the project, such as the data collected, the implication of children, patients, their consent to the research, data protection, and all ethical aspects of the project. A first meeting took place in Feb 2015, and the next meeting in November will review data collected so far.

### Training – Key to Patient Partner in Research (PPR), by Francesca Marchiori

Francesca started with a quote, “Nothing about us without us. Involving patients in research projects improves both the methodology and outcomes of the research, and offers invaluable additional insights. It is essential to ensure that high quality research brings real benefits for patients and their daily lives.”

Research is done for patients. Without them there is no reason to do research. The objective of EULAR is also to move them from the passive role of being co-opted in a research as guinea pigs, to a more active role in all phases, and for all research types.

To be effective, the Patient Partner in Research (PPR), needs to be equipped as equal to the researchers. This implies that patients gain in personal skills such as communication (including language skills), motivation, being constructive, etc... They need support from experts who already know the methods, but also from all patients, as the PRP must speak for all the patients, not just for his/her self. His/her experience is important but should be integrated with the interaction and the listening to other patients and patients' organizations.



Eupati training seeks to have 100 trained people for all diseases.

It is interesting to have general training to enhance patient participation (project organization, Delphi method, ...), but also specific health related training (on clinical trials, health technology assessment, ...regulation & reimbursements, organization of health care). A number of organizations make that training available (including PARE, EUPATI, EURORDIS).

But for lupus, additional training is needed because your lupus is different from another's: understanding its complexity, complication, and also its impact on social lives and various treatment options is very important. In selecting the appropriate training, one must be careful to confirm the reliability of the information (not everything on internet is true), as well as the depth of expertise required: Patients don't need to become research specialists, but need to understand the medical research language.

Francesca then shared her thought that similar training is also important not only for patients, but also care givers, nurses, doctors (GP) so that they can include lupus thinking even when just dealing with a “normal cold”

Finally, Francesca insists that PRP need to install two-way communication: On the one side, sharing experience & outcomes of research, on the other side, getting information to better play the PRP role. This requires new efforts to be made, which could include surveys, social network usage, meetings with patients, or groups facilitating interactions among PRP. Many people are involved in projects that could share their thoughts more frequently.

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After the coffee break, Anne Charlet introduces the second session, focused on “Communication”:

### Engaging to make things happen, by Nuria Zúñiga

“I was an Echo, but we need people to be their own voices”. Nuria explained how lupus changed her life and how getting into social media saved her life - she could identify a new goal, when she thought everything was finished. She started her own blog helping patients as other patients had helped her. She did not know about lupus groups, and so worked on her own. Many independent patients on social media are raising voices and are contacted by pharma companies. Nuria felt like she could reach the moon.



But she soon realised that once you have reached the moon you might feel alone like the “Petit Prince” of St Exupery. Joining patient associations, rowing in the same direction, achieves a lot more and truly makes change happen. You can be a voice, but it is a lot better if we can all have the same voice and talk together. Most of the 5M patients around the world are not in associations, and we are not taking advantage of their energy and power to change things. Nuria leveraged social media to reach out. She has ca 2500 visits/day from people asking about treatment, sex, side effects, talking about their fears, .... Social media and blogs give visibility on what organisations are doing. Going on social media to say where we need volunteers, explaining that you join a meeting, ... you make your effort known and contagious. We need to hear not just about miseries and weakness, but also progress and success.

Nuria advocates that while we are doing many things, unless we communicate enough, we won’t get more people to engage. Social media also helps connecting with the people that you represent: making sure people see what you actually do, what you say, makes them already participate into your effort.

Anne expresses how important it is to be trained to properly blog & tweet. Nuria is an expert in that, and might help you grow that skill.

### Message to Share, by Augusta Canzona

Augusta explained how the patient groups’ role is important in informing members, helping them through counselling, self-help groups, and psychological support; but also to help train doctors. Sharing information about treatment (what exists, its importance, ...) in conferences with multiple targets really raises awareness. This can be done in doctor-patient meetings, educating patients or volunteers, disseminating information, ... It is important that patients are aware of the treat to target initiative and of what a treatment strategy can look like.

In Italy, two specific activities are at the core of patient/doctor interactions : (a) Lupus Clinics are centres with multifunctional teams in all medical branches involved in lupus treatment, offering a unique point of contact (including for the family doctor), help-desk with priority access for emergency assistance, easy access to diagnostic resources and instruments and access to new, off-label, treatments; and (b) Training for doctors, through the tri-annual Pisa course for which Lupus Italy funds up to 10 bursaries. The course targets young rheumatologists and fosters international collaboration among experts, focusing on major clinical, pathogenic and therapeutic aspects of SLE.

Lupus organisations also can drive action and support to patients, particularly in the current financial crisis, where they can help avoid budget cuts affecting lupus patients, as well as help patients in financial difficulty find support.

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To support this lobbying role, Lupus Italy collected, through an on-line survey, information on un-met needs and quality of life, with a special focus on joint pain. This research was developed, organised and interpreted by patients, with researchers' support and obtained 550 patient responses. Interestingly 40% reported coexisting diseases, 55% get treatment in hospitals, but only 21% in lupus clinics. 83% reported bone and joint pain as a symptom or side-effect. Patients' working life is the most affected, and 64% of patients are disabled workers. Lupus Italy is now using this research to improve awareness of patients' situation at different levels and identify key issues (pain, access to resources, early diagnosis) to be further developed.

### Messages from patients to groups, by Alain Cornet

Alain explained how the Helsinki LUPUS EUROPE Convention resulted in a patient panel focused on treatment, during which 10 diverse patients from all over Europe exchanged thoughts on adherence to treatment. One of the by-products of this panel has been the writing of 3 letters: one addressed to fellows living with lupus, which has been further used as part of the WLD "tame your lupus" campaign, one addressed to the medical community, which has been further developed as a poster presented here at ICL, and one containing the key messages that patients want to convey to Patient organisations.



This message starts with a big "Thank you", and it is important, as patient leaders that we realise how thankful patients are for our support, information, and the role we play in breaking their isolation and forming a community. They urge us to reach out further to dermatologists or smaller hospitals to help a newly diagnosed person find community and support. Patients ask us to bring hope, encouragement, support and energy rather than a "sickness competition".

They look to us to bring objective information, create moderated and reliable platforms to share experience and get answers from trained experts. They seek affordable and understandable literature, as well as tips on best practices and standards of care.

They also view our role to promote access to affordable treatment with right standards of care, reducing delays in treatment or duplicate testing, identifying lupus centres or clinics adhering to EULAR standards of care, and lobbying for access to sunscreen, particularly in the southern countries.

They also want us to convey to the general public, administrations and employers that even if we do not appear visibly sick, lupus has its toll on our health, but many of us can live almost a normal life if modest adjustments are made.

Finally, they offer to help, but starting with small things, so that, at the pace they determine, they fully take their place to help improve quality of life for all people with lupus.

In closing, Alain highlights that 6 videos have been produced with the support of UCB, providing direct testimonies of the participants on many aspects of lupus in their daily lives.

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### Saturday September 5, 2015 – Hofburg Congress Centre – WORLD LUPUS SUMMIT

Kirsi Myllys, Treasurer of LUPUS EUROPE and Convention manager, welcomes all attendants to the 26th LUPUS EUROPE convention and the 1st World Lupus Summit for patient leaders, and welcomes Sandra Raymond from LFA.



#### Introduction, by Sandra Raymond (USA):

Sandra introduced the session by acknowledging the many challenges we face living with lupus. Why do we not know the causes of lupus? Why do we not have the medications we need? The drugs development process is not suited to lupus' many faceted diseases. To resolve that, we need to work strongly with the industry, but also at national institutes for health that do independent research on diseases. In the US, the arthritis institute deals with 99 diseases, but is short of money compared to other disease areas. The definition of lupus is very important: if we want resources flowing to lupus, we need it to be considered as an auto-immune disease, which is what it is, rather than arthritis. If we define lupus into arthritis, the money will flow to arthritis, not helping us much. Sandra also explains her awareness campaign **kNOW LUPUS**, in which many celebrities are involved. Lupus is a global issue, a significant public health issue, and we need all global efforts to work on it. As was done during the last chapter of LFA, she invited us to take lupus from a whisper to a SHOUT.

#### Landscape of Lupus Groups in Europe, by Blanca Rubio (Spain)

Blanca explained that as part of LUPUS EUROPE's strategic plan, "Members" was defined as a priority. A survey focused on understanding member group's aims, structure and resources, the situation of people with lupus in member country, and their needs. The outcome is that our variety is incredible with groups from 10 to 6,000 members, for a total of about 30,000 members across Europe. While this is much, it is only 6% of all patients, so this is a call to get more people in.

Most organisations are directly or indirectly dependant from Rheumatism organizations, and all except 1 work exclusively based on volunteers. Funding is typically limited, with the vast majority of associations funded mainly from membership fees. The request from our members is for support in advocacy work, ideas on how to better work with volunteers, and education / engagement to drive lupus patient interests.



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European lupus groups show a diverse range of capabilities and resources, most have limited resources without possibilities of hiring any professional, and need capacity building in priority areas.

### Challenges, opportunities and diversity, by Kirsten Lerstrøm (Denmark)

Kirsten broadens the discussion on to some of the other strategic drivers of LUPUS EUROPE's strategic plan: (a) People with lupus in Europe participate in and benefit from lupus research, (b) LUPUS EUROPE member organizations are enthusiastic and empowered, and (c) LUPUS EUROPE is heard and acting.

Many opportunities exist for research, new funding routes, partnering in projects, but we also face the big challenges of engaging *enough* people in a volunteer based structure, and mobilising the funding and networks. To these challenges faced by many groups around the world, Europe is on top confronted with the difficulties of different countries, capabilities, approaches to treatment (with lupus centres emerging only in few places). She concludes that it is up to us now to define how we want to progress, towards a global organisation that deals with those specific constraints and turns them into opportunities.

### From Grassroots to Regional groups, by Dalilah Kalla (Mauritius):

15 years ago, Lupus Alert started its journey towards hope, grouping people living with lupus (patients, caretakers and friends) together. In 1999, two years after being diagnosed, Dalilah Kalla decided to speak openly about lupus and raise awareness. Her aim was to meet people with lupus to get and provide the moral and emotional support needed. Since the article went in the press, with her home phone number, the phone rings regularly with people saying "I have lupus"...

Lupus Alert engages in multiple activities including raising awareness, visiting schools or patients, bringing information through a library. "Many patients cannot come to us, so we need to go to them" said Dalilah. In Mauritius, public healthcare is free at the hospital, including sunscreen, but some treatment is not available there, like bone densitometry. Lupus Alert provides those treatments, helps people get access to adequate care when needed, and reminds them of the importance of staying active and celebrating. Lupus Alert also connects externally with patients around the world, and would welcome your support and visit!

Lupus Alert is essentially people, based on volunteers, full of passion and determination, ordinary people doing extraordinary things!

### Organising local groups to federal political player, by Diana Gray (USA)

Diana offered us the thought that "Great things are done by a series of small things brought together". We may be small individually, but collectively we can have great impact.

LFA was founded in 1977, with local organizations joining as chapters and developing scope and reach. In 2014, an Integrated Strategic Plan was created, linking Chapters and National level into the vision of "a life free of lupus". It defined as strategic outcomes the reduction of time to diagnosis, safe and effective treatment, expanded direct services and increased access to treatment and care. An additional objective is to increase support so as to achieve the outcomes.

Each LFA chapter is legally independent, and signed an LFA affiliation agreement that ensures commonality of goals. LFA currently has 17 Chapters (ca 50% of the geography), one region (New York), 2 volunteer managed Partner Organizations and 267 Support Groups. This is supported by more than 100 staff. The central structure acts as a service provider for the chapters, offering staff support, marketing materials, templates, model legislation, Magazines (Lupus Now and Lupus Science & Medicine), and a Centre for Clinical Trials Education. It also ensures through its affiliation agreement that affiliates observe standards.



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In terms of public influence, LFA developed a network of 200 Advocates that they bring together every 2 years in Washington, DC to educate Members of Congress. LFA trains them on important messages and organizes meetings with Members of Congress. Many things have been accomplished through action at Washington level, including raising investments in research, funding education for minority doctors, ...

LFA also receives funding to ensure that patients are at the centre of research in many organizations. This allows them to participate in those projects or organizations and promote patient-centric approaches.

Diana concludes that, with a disease that impacts approximately 5 million globally, we must come together at global level, as was done nationally in the US, and show our strength.

### International Lupus Federation Workshop, lead by Robyn Rickenbach (USA)

Duane Peters (LFA) introduces the workshop highlighting the importance of a focused common vision and message track to raise one voice around the world. As preparation to this meeting, a group of 9 countries (USA, Denmark, Italy, Canada, Australia, UK, Finland, Indonesia and Argentina) started the thinking to define what a lupus federation could look like, and what its top priorities would be. Today's session will seek to get a broader input from this audience before concluding and driving possible next steps.

Robyn Rickenbach opened the workshop by asking each country to say its name and give one word about the world federation project: Hopeful, great, opportunity ... are often coming up

She then asks participants in the pre-meeting to express their key take-aways from the London meeting. Three key take-aways emerged: (a) The day was quite positive, ending with a feeling that "we can do it". (b) We need to find **how** to do it, but we need it, and (c) A federation will not replace local country groups, but help them grow.

The panel then answers questions from the audience: There is a conviction amongst panellists that such a federation will not bypass smaller countries, but rather enable them to grow their capabilities. Regional groups have a role to play as the commonality of issues is bigger at regional level: Europe will keep its role, Asia pacific should grow, Gladel is taking initiatives to unite patients in Latin America. No group will lose its local colour because each group is as important as any other one, the smallest as important as the largest. We do not want to leave anyone behind.



LFA explains that a federation can help share material, develop a common program, training, sharing of what works well, ... Lupus UK is also very ready to supply information, books, leaflets, booklets, video's, DVD, ... to those needing it. Events like WLD have been gradually embraced by many and are now used for fundraising, awareness, conferences, ... This is a good example of uniting idea, where necessary flexibility has been identified (many celebrate WLD on a day other than May 10). Each country has their own colour, and can best organize their campaigns in their own way. The goal is to have an inclusive process. The federation could offer a website for communication, help enrol celebrities, have existing ones better reach out to the world.

The panel highlights how each group can help the start-up effort. A simple, but necessary action is to respond to emails, take part in the federation, share thoughts and findings, participate. We need communication because if we don't know what each other is doing or needing, we can't include it. Inclusion emerged as the key theme that is raised in the discussion.

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The audience is then divided in 3 subgroups, and rotates through flipcharts to answer 3 key questions. The detailed feedback received will be later distributed and is not included in this report, but here are the few words highlights for each topic:



On “What key long term positive do you expect from ILF?”: Awareness, sharing of information, better quality of life

On “What would make success?”: Democracy (big worry – how will my voice be heard), Unity and Common goal (working in the same direction), Funding (won’t work without money)

On “What one service would do the most to advance the cause?”: Awareness campaign (including celebrity involvement, ...), Safe treatment for all (access to drugs), Capacity or skills training.

Duane thanked the audience for input. This federation should unite all of us and help to reach common goals.

From this material, the steering team will enrich what has been designed so far. A group of five countries/area will close on a final document that will be sent to each of the organizations, also mapping the next steps in the organisation process and defining a strategic plan so that by the next congress we will have plan and actions!

### Afternoon session

After a Group Picture, Katharine Wheeler (LUPUS EUROPE Trustee) introduces the afternoon session looking at Lupus groups around the world, under a theme “Aspirations and inspirations”: We all aspire to a better world for people living with lupus, and we can find inspiration in this shared experience.

### Videos from Latin America:

The Latin American countries could not attend, but have sent us video messages where Teresa from ALUA (Argentina) explained how ALUA developed its activities, culminating with the patient forum at ICL 2013, which allowed getting access to media and raising awareness. She expressed the hope that a global federation will bring us to the next levels.

Gonzalo Tobar, from Lupus Chile remembers the success of ICL Buenos Aires. Lupus Chile was created in 2008, and aimed to work for everyone with lupus in Chile. He also commends the great work done by Nuria through her blog, which is bringing answers to many people in Latin America. He invites everyone to take a picture of him/herself “I am lupus” and post it on the lupus Chile website where they have a wall for that. This is a first great offer for collaboration across continents. He asks that all of us be the voice not only of our groups but also of the 20,000 people living with lupus in Chile.

Shirley Sanchez, the chair of ASBOLUP (Asociación Boliviana de Lupus) explains the challenge they face in terms of helping patients, but also the society as a whole to better understand lupus: no statistics exist and many people have limited access to treatment. The group also tries to lobby for patients with the government so that they get involved in handling their care. They regret not being here in Vienna, but would like all of us to work together towards better education of patients and governments.

### Inspirations from North America, by Tanya Carlton (Canada)

Tanya presents the changes that have taken place recently in Canada. Lupus Canada’s vision is a Life without lupus. Over the past year, they launched many programs, one of which was to grant Scholarships for students with lupus pursuing post secondary studies, so that they do not need to work to pay their studies. They helped fund the launch of a National Lupus Registry of all patients to an online platform, so as to help research. They also created a facebook page

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dedicated to youth and one with just Information. One of the issue they face is being bilingual, hence need translation of all they do, which is quite expensive. Lupus Canada also developed ambassadors. Their expectation of an International federation is increased awareness, help for smaller organizations, a better sharing of information, and support advocacy. Canada created 12 lupus educational videos, which also help increase awareness via web and social media. Tanya shares one of them with us, inviting to reach to their website for more!



### Inspirations from Europe, by Augusta Canzona (Italy)

Lupus Italy has 2500 members and makes several awareness events, for May 10th (WLD) (which they make on the closest Saturday), and a public awareness month in October, including fundraising. They would love to identify an ambassador that could raise their voice. Lupus Italy staffs a free-phone help line from 9h to 16h on week days. Lupus Italy operates through 13 regional groups that are close to the people, organizes conferences and provides assistance and information to patients. Lupus Italy supports 7 lupus clinics through the employment of one or two medical doctors in charge of the Centres. They also support the Pisa SLE Course (once every 2 years) with up to 10 bursaries covering registration fee for young rheumatologists.

Lupus Italy's funding comes for 66% from income tax donations, whereby people can assign 0.5% of their income tax to charitable organizations. Membership is only 8% of fund raised, and Lupus Italy has creative ideas to increase its income, such as getting a small amount on each pizza sold from 12 pizzerias: It is small in amount but big in awareness, and spreads in social networks.

### Inspirations from Asia, by Eko Pratomo & Ayu Bisono (Indonesia), and Marilyn Robles (Philippines)

Eko Pratomo of SDF Indonesia presented a great video on Lupus Indonesia SDF. This infographic is a good example in itself of the tools that SDF uses to spread information on lupus. Another achievement is the booklet "The Lupus Tamer", initially developed in Indonesia, which LUPUS EUROPE has adapted in English and French. This is another great example of win-win collaboration between lupus organizations around the world, and more languages are welcome. Eko, Alain Cornet and Bernadette Van Leeuw proceed to a formal exchange of the brochures as a tangible sign of this passing on of material, and then hand over the French version to all countries where French is spoken (English version will be printed at a later time, and is only available as PDF for now).



Ayu Bisono from Yayasan Indonesia, the other National lupus Group in Indonesia, expands further, explaining the issues faced in the huge archipelago of Indonesia. The dispersion of the population is in itself a challenge, and the population is huge, so each of the two groups have their separate reach. Yayasan operates with 13 groups over 4 key islands. Standards of care and treatment information would be most welcome, but is difficult to distribute to doctors throughout all Indonesia. One of the big issues faced by people living with lupus is the cost of treatment, as the government typically funds only 20% of the treatment cost. Further, Mycophenolate Mofetil costs (\$2/tablet), and Albumin Human Protein (\$150/ bottle and you need 5!) are not reimbursed at all because they are considered "off label". This is a real issue as a majority of lupus patients have lupus nephritis. And Yayasan brings visibility to high levels: a team of Yayasan members went all the way up the Himalaya on a fund raising trek to raise awareness to new heights!

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Marilyn Robles from the Lupus Foundation of Philippines presents their work. For a 100M population spread over 7,000 islands (3 major ones), there are only 120 Rheumatologists, and no count has been made or estimated of lupus patients. LFP has now created 8 lupus support groups, in the biggest metropolitan areas of the 4 largest islands. They hold monthly meetings on the first Saturday of each month, participate in clinical trials, and raise awareness in local media and through their publication “Soaring Butterfly”. Their aspirations are to undertake a National awareness campaign, work with universities to introduce lupus to health professions students, and better link the provincial support groups through regular meetings. They also would welcome being involved in the international lupus community.

### Inspiration from the Caribbean, by Reeanna Harrilal

As the final presenter in the session, we welcomed Reeanna Harrilal from Trinidad and Tobago. Up until a week ago she did not think she would be able to join, due to financial constraints, but the money arrived at the last minute. For the first time, the Caribbeans are able to attend such a congress. Reeanna’s journey has been tough with lupus from childhood, but “gone are the days to believe it is a death sentence”, she moved from sitting in a corner and seeking to end her life to saying there is hope and we have a purpose. We can establish a world federation, where all our work put together can achieve a lot. Being a journalist, she used that skill to become an advocate of lupus in Trinidad and Tobago and beyond in the islands, so that one voice sitting in a corner can now resonate beyond the border of the island.

Before closing the session, Nuria Zuniga, that has been tweeting on our behalf during this day announced that we have reached 944,000 impressions on Twitter: Almost 1M people have heard about our world patient leader summit. Our voice already starts to be heard.



### Lupus 2017 – Melbourne, Australia and Autoimmunity 2016, By Professor Yehuda Shoenfeld

Representing the organizers of the next International Congress, Professor Shoenfeld is closing the day with an invitation to join ICL, in Melbourne, from March 26 to 29, 2017. However, as autoimmunity is very close to his heart and



dedication, he gives an informal presentation on why is it that the immune system reacts so strangely when it comes to lupus. There is a genetic compound as well as a reaction to environmental factors. He believes strongly that also helminths in the digestive system play an important role. However, there is no fact or solid evidence of what it is that triggers lupus. The note on next International Congress and the informal and charismatic presentation triggered a host of questions and comments from the audience interesting subjects – it was a fine way to end an extraordinary lupus day!

In the evening, World summit participants enjoyed a performance from Kim Spierenburg, a young Dutch violinist living with lupus since she was 7 years old. Kim explained how playing violin has become part of her “medicine” and how she finds energy to stay optimistic by living her passion for the music. She invites us all to find our own violin, the passion for something that makes us live our lives to the full, despite lupus biting us.

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### Sunday September 6, 2015 – Leonardo Hotel – Vienna – LUPUS EUROPE COUNCIL

#### Sun, Skin & lupus

We start the day with a discussion with Professor Annegret Kuhn on sun, skin and lupus. Professor Kuhn has worked for 20 years on Lupus in dermatology and chairs the European Society on Cutane Lupus Erythematosus (EUSCLE). With that group, she is working at setting new guidelines that doctors can use to give advice. Annegret also won the Galderma Skin Pact Award for Community Leadership at the Skin Congress in June that will help fund on a project prospect a pan European study on clinical advice on sun protection and reimbursement of costs to patients.

In the morning session Annegret presents the EUSCLE recommendations, which are still confidential, and asks for our feedback and comments on those. 70% of lupus patients have some dermatologic signs, so it is very frequent. From a classification, Cutaneous lupus (CLE) is for people who mostly have skin manifestations, but many also have Systemic Lupus (SLE) at mild or severe levels. The recommendations are addressing CLE and SLE patients with skin manifestations. So far, no drug has ever been approved for skin, so everything we do here is off label. Some trials have taken place, some drugs are in process and we are confident that there will be some specific treatment for skin lupus soon.



In 2009 German guidelines were developed with a 3 step protocol: 1<sup>st</sup>) prevention (UV protection, but also nicotine abstinence), 2<sup>nd</sup>) Topical/physical treatment (corticosteroids, Topical calcineurin inhibitors and more), and 3<sup>rd</sup>) systemic treatment, with the full 3 levels of SLE type handling.

Annegret interacts with the team on the recommendations. The slides will be distributed on a confidential basis, and LUPUS EUROPE will collect feedback that will be sent to Annegret.

Annegret then addresses the situation of sun and skin. UV is an important factor in the pathogenesis of LE, and while sunscreens are safe and cost-effective preventive measures, there are challenges with insufficient recommendation for sunscreen application by physicians, lack of information to patients, and lack of reimbursement (UK is the only one in the room where sunscreen is provided free of charge). A German lobby project is started, which leads to a survey underway in Germany (with setting up of a randomised trial) to backup the claims.

The project is now to have a web-based questionnaire covering all of Europe to assess parameters such as frequency of application, sun protection factor, amount of sunscreen, and the efficiency. Data will be collected centrally. The questionnaire will be translated. This should help drive prevention of flares, lower disease activity, and reimbursement as a goal.

Lupus UK offers that they have a great booklet to share on the issue of sun protection.

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### Council Session – Notes reserved to Council members

See Council minutes

#### Panel on Treatment:

After the council session and lunch, a workshop on treatment took place as a follow up to the Helsinki Workshop, Brussels patient panel, and in preparation of the next panel on treatment.

A key element of living with lupus is the need to continue treatment over the long run. While following treatment carries the promise or the hope for a better life, it also brings constraints, day after day recollection that the disease is there even if not active, and multiple side effects that accumulate over the years. Treatment in itself can then be perceived as a burden on quality of life, and adherence to treatment diminishes.

A first patients' panel wave explored the concept of treatment in general, as well as key factors affecting adherence to treatment, with a focus on core treatment in a hospital environment, through infusions. The working definition of treatment that was used is as elaborated in Helsinki "Any product or activity that aims at improving the person with lupus' quality of life." and this includes core treatment, medical and well being (quality of life).

The patient panel resulted in three letters being written (to doctors, patient organisations, and people with lupus), as well as 7 videos (Message to someone just diagnosed; One disease, many symptoms; Myths and misunderstandings; What it means to friends and family; My life with lupus; Hopes for the future; The importance of World Lupus Day).

Convention participants were split in 4 groups and asked to consider how best to use each of the materials that came out of the first panel.

With regards to the letter to the medical community, suggestions were made to (i) invite yourself to present at medical monthly meeting, in doctors training session ("meet the patient" for trainees), or (ii) to translate the letter, copy it on your national organization's letterhead and drop it into the suggestion box, (iii) leverage in T2T in short form for quick reference, or (iv) translate and submit to medical journal for WLD, or even transmit to Ministry of Health for further diffusion(?).

The letter to patient organizations raised the question of better direction of good quality information. We could react to that by having a Twitter style headline which is repeated once every day for a week, to survey member groups on how to better use information, but also to search for best practices: diabetes, MS, cancer patient groups.

The letter to patients is a great tool particularly for newly diagnosed people. it should be available on webpages and blogs, through patient organizations. hospitals and outpatient clinics. An idea would be to have a welcome pack at hospitals (with additional info, etc...). It would be good to always have copies to hand out, particularly if they are personalized by adding contact information, and visually more catchy.

With regards to the videos, the message on the invisibility of the disease was perceived as the most important. Some mentioned that a campaign for awareness can be positive or negative, and that a preliminary video expressing a vision for hope and inspiration would be very beneficial. The videos should be available for use by a broad audience:



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employers, neighbors, community, school, newly diagnosed patients, pharmas, doctors and the society in general. Next videos could focus on more hope/inspiration, and lessons on how to live with SLE including professional expectations.

Our next wave of panels will focus on the burden of treatment over the long run, looking at how day-to-day repeat treatment is perceived by lupus patients, and what learning we can take from that understanding to improve the quality of life of people living with lupus. To prepare for this next panel, the teams focused at identifying those questions that should be raised in a next panel and/or in a patient survey. The proposed questions can be grouped into:

Highly qualitative questions, suited to a panel:

How do you view day-to-day treatment? Is it the same everyday? What negatives do you associate with it? Is any part of the treatment more negatively tainted? Is there something that would make it easier to accept pills for life? (what?) Could technology help remind or motivate the person (an app? Something else?) What could make us adhere better to treatment? What did you change to improve? How did you collaborate with your doctor to improve your treatment? How did you get information and confidence to talk with the doctor? How did the struggle with benefit/burden influence you psychologically? Does the number of pills affect how you take them?

Containing an element that could be suited to a questionnaire:

Do you use technology to help remind or motivate you to take your treatment?

Are taking pills part of your daily routine (if no, why not? If yes, how did it become routine?)

Would visualization vs text help adherence?

Do you think you are well informed on treatment?  
Risk / benefit?

Do you feel you can question your specialist? Do you listen to the doctor? Do you follow the prescription strictly, or do you “self administer?” What pills do you skip, what not? When? (Why?) Do you tell the doctor when you don’t take pills?

Questions around packaging (in portions?), dosage boxes, amount (why so many), taste (coating with flavor)

How do you view D2D treatment benefit/burden? (in relation with duration/part of the disease cycle: - at start, after symptoms diminish, in the long run)

Do you feel like medication works despite side effects? Did you feel more sick with a new medication?

Have you experienced side effects? Did they get better over time? Did your doctor inform you about side effects?

Is your treatment individualized?

Where do you learn about how to take the medication?

Does your medication affect your mood? Your energy?

Do you have troubles getting the pills? Is there an impact of costs? Availability? Prescription vs. supply you’re your prescription the same as supplied by pharmacies? Is the drug too expensive and therefore not prescribed?

Do you take your pills even in remission? Do you take them only if you feel badly?

Does your family have an impact on the way you take your medicine?





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This appreciated input will be used by Davide Mazzoni, Bernadette Van Leeuw and Alain Cornet to prepare and organize the Patient Panel II, early 2016. This panel will use Interpretative Phenomenological Analysis to deeply and systematically analyze data, with the hope to lead to publication & further usage

Members are asked to support by identifying 8 or 9 patients for the Panel. These should be “new” people, uninvolved with LUPUS EUROPE so far, and preferably also little involved in running the local organization so that they express an unbiased, “untrained” experience. They should speak fairly good English, and be of geographic, age and gender diversity. As a prerequisite for attending the panel, they will need to have a 45 minutes Skype interview, recorded and transcribed.

With regard to the other questions, we are considering a questionnaire on the burden of lupus, particularly on the aspects on treatment on the long run (pills for life). This questionnaire would be distributed through different channels (including via doctors and via local organizations) to check potential bias. As funding and specifics remain to be agreed and discussed, we will come back on this initiative at some later point.

The panel is closed on this final note, and Kirsten closes the convention, inviting everyone to join us in a year for the 2016 Lupus Europe Convention, in Würzburg, Germany.

