

**Patient Panel 3 project report**  
**LUPUS EUROPE YOUTH PANEL**

**Executive Summary:**

*On May 18-20, 2018 LUPUS EUROPE organized a Patient panel, bringing together 10 Lupus affected young people from all over Europe to share their experience of living with lupus. The people were selected based on individual applications after an announcement sent through LUPUS EUROPE members network. The Panel was conducted through a series of interactive presentations, team discussions and working groups. From Friday afternoon to Sunday lunch, we addressed the key issues they identified in their life with lupus.*

**Some key learning:**

- *While they considered taking pills every day as a key problem, they preferred to focus on the collective issues of being understood by friends and family and having to live with limitations.*
- *A big “Wow” was the feeling of guilt expressed by several female participants (guilt of imposing limits to their partners, guilt of not being able to do as much as others, ...). This guilt seems to be a very important underlying dimension of their social and affective life, which is likely much misunderstood by doctors and patient organizations;*
- *young people with lupus remain fundamentally more positive on their life with lupus than the average patients. Their messages to other young people with lupus are reassurance, and positivism, and while they perceive lupus as being “all over their lives”, they want to make sure they are not ruled by it, and want to have no obligations relating to it...*
- *With regards to the future of a LUPUS EUROPE youth group, they rather view it as a “virtual group” on social media, with minimal commitment required, but bringing together “friends” around highly visual messages, short stories and the exchange of ideas that could lead to small group gatherings.*
- *On the medical front, when we probed what would drive them to consider joining a clinical trial, clear first media is their lupus doctor, second are national lupus groups and LUPUS EUROPE. Other medias have a very limited impact.*



*Two topics of a more scientific nature were addressed: participation to clinical trials, and an open Q&A session with professor Frederic Houssiau.*

**BACKGROUND:**

After its 2013 Convention in Paris, LUPUS EUROPE engaged on a project to conduct Patient panels, bringing together 10 to 12 patients with limited or no specific lupus knowledge, to gather qualitative feedback on specific lupus related issues. These panels have in common that they bring together “naïve” (i.e. with no particular knowledge or active engagement in advocacy) people living with lupus, to discuss

topics identified by LUPUS EUROPE, under the lead of facilitators themselves living with lupus. The focus on “by people with lupus, for people with lupus” enables a direct personal connection, and a climate of “being in the same family” that reduces the pressure and allows any participant to have his/her own answer rather than a perceived “right answer” to be given.

After 2 panels dedicated to aspects of treatment, the 3<sup>rd</sup> panel focused on YOUTH. Across Europe, national lupus groups have a difficulty in reaching the young people with lupus. Few commit time to local organizations, most people only join actively years after diagnosis, when they reach 35-40 years. This begged to question what we, as LUPUS EUROPE, should do about youth, and whether specificities should be considered to address this population’s needs and relay their voice.

### **Participants:**

As for the prior event, the patient panel was conducted by and for people living with lupus. The organization and the facilitating of the panel and its workshops/discussions was done by Jeanette Andersen (Denmark, Chair of LUPUS EUROPE) and Alain Cornet (Belgium, LUPUS EUROPE Secretariat).



The panellists were recruited through LUPUS EUROPE’s network, seeking to bring in “new people” in the discussion, as representative as possible of the Lupus European community. All agreed English would be used as the working language. Participants were: Elena (Italy), Cassandra (France); Ronja (Germany), Raquel (Spain), Heini (Belgium), Valeria (Italy), Zgim (Netherlands), Agne (Lithuania), Santhia (UK) and Rudolf (Hungary). All aged between 18 and 27. One participant from UK cancelled last minute due to health. Participants did not know each other and had no contacts with each other prior to meeting in Brussels.

### **Prior to joining:**

Ahead of joining the panel, participants were required to provide input on two questions: One was to list their top challenges or issues living with lupus. The inputs received for this question were used for session 1 of Saturday AM. The second question, asking about their key questions for the panel was used to design the program itself.

### **FRIDAY MAY 18 PM - INTRODUCTIONS:**

The face-to-face panel started on Friday May 18 evening with an opening session around a drink where each participant introduced him/herself and his/her lupus story. Participants also had the opportunity to voice their hopes and/or fears ahead of this panel. Positive relations and trust were quickly established, and the young people immediately went into interaction, much faster than what we experienced in previous panels with mixed age groups. The introduction session continued with an informal dinner in the hotel restaurant.

## **SATURDAY May 19 AM:**

On May 19, the day started with a presentation of LUPUS EUROPE and how this panel fits into LUPUS EUROPE's strategic objectives and reason for being, a discussion of the Panel's objectives, agenda and deliverables.

### **Session #1 – Challenges and opportunities**

As pre-work, we had asked the participants to come up with their 3 biggest challenges when it comes to living with lupus. That input was written on a large flipchart which was revealed at the beginning of the session. Each participant could then associate his/her own experience with the statements made by others, by adding a small "Me too" next to the issues listed that resonated well with them.

1. Taking pills every day, being understood by friends and family, and having to live with limits (like avoiding sun, ...) were the 3 most commonly faced issues with 7 "votes".
2. Mood change, waking up in the morning, and remembering to take medication when routine change followed with 6 votes each.
3. Coping with fatigue, fatigue and pain, and changes in lifestyle came next with 5 votes, i.e. being faced by half the participants.

A very large range of other issues were faced by 4 of the participants: balance rest with social life, limits on activities, hair loss, weight change, mental health, feeling caged in my behaviors, facing pain and having to do as if it was not there, distinguishing lupus problems from generic symptoms, thinking at lupus "all the time", comorbidities (getting other related illnesses) or "pain in my bones/articulations".

Finally, a number of other issues were only mentioned by 3 or less participants: Get other doctors to take me seriously, having to argue with doctors, nurses, hospital staff, focus on a strict diet, managing a normal social life, influence on career goals, hospital time out, eye strain, memorizing facts and Not being as fast and successful as my friends. Interestingly, when asked in the prework to define their top 3 issues, the 11 respondents came up with 29 different issues (i.e. only 4 duplicates), but when reacting and associating with the statements of other young people, 9 issues gather a majority consensus, and all issues quoted have at least 2 votes. This very much shows the mix of heterogeneity and commonality of the experience of living with lupus.

After discussing each item, we asked participants to come up with some positive things about living with lupus, writing them on butterfly-shaped post-its and fixing them to the same flipchart. Among items highlighted by participants: love for my family, forgiveness, perspective, prioritizing, people who really



care, prioritizing, talking better care of my body, new friends, strong, not to be scared of blood taking anymore, self-confidence, knowing myself better, empathy, maturity, routine, self-forgiveness, being independent and accepting my condition, strength, knowing my strengths.

A view of the colourful butterflies spread out between all the challenges illustrates perfectly how having lupus doesn't always have to be a negative thing. There is hope and positive things even in the darkest hour.

## Session #2 – Lupus and My Social Life

Based on the topics wished for discussion and on the issues listed, the most common challenges for our panellists connected to their social life, which we decided to focus on. This was done in 2 steps: First, identifying what a social life entails (i.e. defining what social life means for the participants), then trying to find the areas which are impacted by having lupus, both in a negative and a positive way.

The panellists felt that most of their identified social life challenges were “youth specific” issues and would not have existed or have been very different, if they had been e.g. 20 years older.

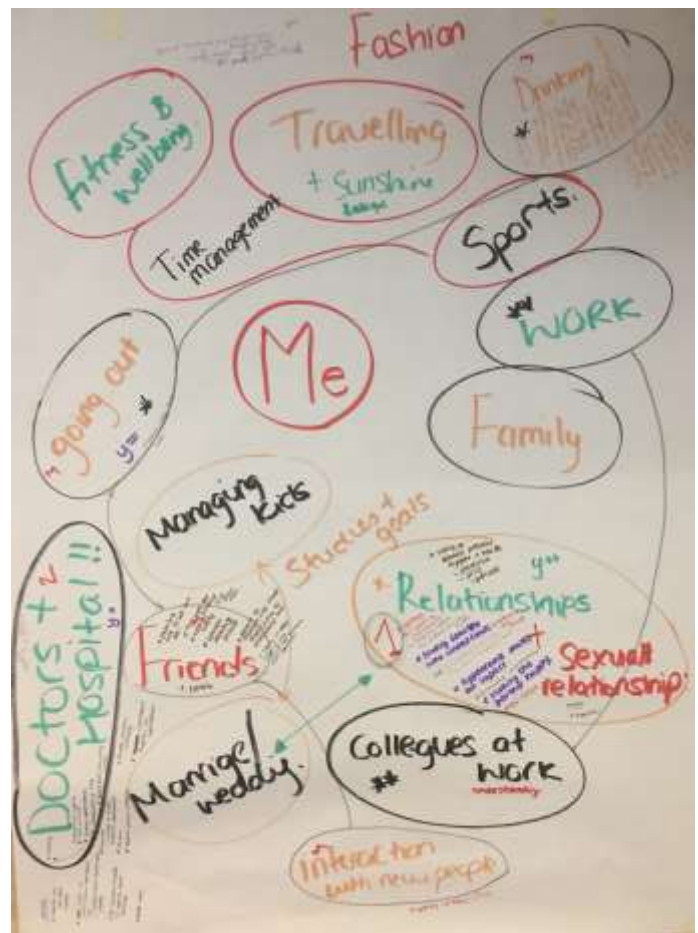
Group 1 identified as top 3 items of their social life influenced by lupus: 1. Relationship (including sexual relationship), 2. Doctors & Hospitals; and 3. Going out/drinking.

Group 2 selected as top items 1. Family, Partners & Friends; 2. Active Lifestyle, and 3; Work, School or Education.

Elaborating on the positive and negative impacts for these top areas:

**“Going out”:** young people with lupus very much like going out with friends, like any other person of their age. Yet, while they spontaneously say “Yes” to offers, actually being able to go really depends on how they feel at the time of leaving. Alcohol consumption limitation due to the disease or medication creates an extra barrier. Other limitations include the limited ability to stay late, discomfort with high heels, tiredness, and when activities are in day time, issues with the sun, forgetting medication, or deciding to skip it because it is inconvenient at that time.

**School & Work:** At school key issues identified are tiredness, memory problems, scheduling issues when needing to go to the hospital or medical appointments. They felt that more support from teachers would be needed, starting with educating them on the hidden limitations implied by lupus. With regards to work,





the big question is if full time is possible or not. Key issues include fatigue obviously, but also the worry that a heavy work schedule might make a flare more likely. Another big issue is the guilt of not being able to deliver as much as you expected or as much as co-workers think that you should, being perceived as “weak” or “lazy”, or even in some cases accused of “simulating”.



Partner & Sex life: the picture on sex life seems to differ very much for girls and boys. The male participants did not feel their lupus much affected their sex life, but females considered it a major issue. This is to the point that one of the participants revealed that she refused wedding with her current partner “until we have a healthy child”. Her view is that because of her lupus, she would possibly prevent her partner from having a normal parent life as she might not be able to have children. This inability is almost perceived as an “extra hidden handicap” that she would not want to impose on her partner.

Common issues identified were fatigue and physical pain making an obstacle to sex life; the guilt to say no (“my partner is entitled to a normal sex life, so I feel guilty saying no because of my lupus”), the medications that affect their sex life/libido, and the issues around contraception (limited choice of medication). When it comes to considering having children, the concerns around the long-term health of their children (is there

a hereditary aspect) come first, followed by the questions around pregnancy itself. Future mothers want “absolutely no accident”, they are concerned about risk of miscarriage, and possible health issues for the mother or the baby, and then questions around breastfeeding.

**Session #3 – Coming out:**

Connected to the topic of the social life is the consideration of when, how and if to be open about having lupus, that is, “coming out” in different situations. Do you tell your employer or work colleagues? How about distant friends? Close friends? Distant family? Close family? Partner? Do you reveal it on a first date? Or at a job interview?

We first started gathering some quick numeric feedback through a poll prior to moving to open-ended questions.

## How public are you (on your lupus)?

Overall, the poll results showed a higher level of confidentiality in social media/virtual relations than

	Yes	No	50:50	NA
It is on my Public Facebook	4	4	0	2
On "restricted" Facebook, I say it	4	3	0	3
On restricted Facebook, I explain details	2	5	0	3
On restricted Facebook, I mention day by day or big events	0	7	0	3
I say it without restriction at school	6	1	0	3
I say it without restriction to "all friends"	6	4	0	0
I say it without restriction to close friends	10	0	0	0
I say it without restriction to family (cousins, uncles, ...)	8	2	0	0
In a relationship, I say it the first day	3	6	0	1
In a relationship, I say it after few days	5	3	1	1
In a relationship, I say it after a bit of time	8	0	1	1
In a relationship, I say it when it is really serious	9	0	0	1
At Work, I mention it in recruiting interview	2	5	3	0
At Work, I mention it upfront	3	2	5	0
At Work, I mention it if I miss work	4	0	6	0
At Work, I mention it if I miss much work (ca 2 weeks)	10	0	0	0

expected with only half the participants sharing this in some way, and none "tracing" their lupus life on Facebook. In "real life" relations, close friends are in the confidence, often the extended family, but "regular friends" like school fellows, ... only know it 60% of the time. Most will wait a few days or even longer before mentioning their lupus to a partner in a new relationship, but all will at the latest when "it gets really serious". At work what is striking is the level of "indecision". Half the participants are undecided on whether they would or not mention their lupus, even if it causes them to miss work. Only if the miss is big and hence the disclosure becomes "unavoidable" would a majority (actually all) disclose. The high level of undecided seems to highlight how important the climate (being listened to and confident that you will not be discriminated against) is.

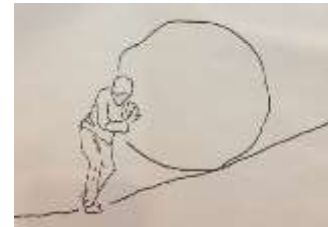
We then divided into two groups to discuss the topic a little more. Conclusions are that participants find it easy to talk about lupus with those people they know best (close family, close friends), doctors (whether lupus specialists or not) or with people that have a chronic disease themselves. Talking about lupus with people you don't know well is a challenge and requires first to build some level of personal link.

When talking for the first time about their lupus, reactions of the audience can vary. Most often there is some type of "I'm sorry" statement, which can be followed by a statement that "you don't look sick", or that people have no clue about what it is. But the overall range of reactions can be much broader:

support, judgement, apologizing, crying, pity, downplaying, overreacting, lecturing, advising, reassurance, or acknowledgement. Finally, some will show through body language that they don't know how to react...



Many will raise questions about lupus, bringing the challenge of what to say, how far to go. Typically, participants will respond with general information about lupus, and how it started with them, then how it continued and its chronic aspects. After pausing which allows the see reaction (disbelief, confusion, encouragement, or questioning), the discussion might go to a more detailed information. Typical questions raised are about contagion, pregnancy, mortality, cure and medication).



Finally, the group practiced a “coming out” in a special way: Each participant was asked to bring a picture or drawing which to them showed their life with lupus. We asked them to form pairs and share their pictures explaining what it meant to them. After three such dialogs, they affixed their picture on the wall, and each of their dialog partners wrote what (s)he heard as key element and what it meant to them. The visuals selected by participants were quite diverse, expressing various facets of the life with lupus.



For some, Lupus is a daily struggle; a wolf you need to live with and can only try to tame. You feel like you are slower than others, facing limitations that your friends do not have.

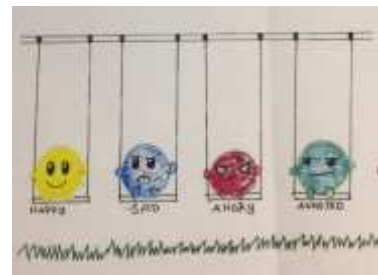


One of the participants perceived his journey with lupus as that of a caterpillar, having to go through various phases, including the cocoon, to finally emerge as a butterfly. He said his life with lupus is radically different than his prior life, but it is like a rebirth to a new way of living”.



In contrast, another participant did not feel there was much to elaborate on: “I have lupus, I just have to live with it, and I want to forget it as much as I can”.

Some of the participants have put the emphasis on specific day to day aspects of their life with lupus, like dealing with pain; having to permanently think at medication or protection (sun, ...) or the daily challenge of emotions and mood changes that are difficult to manage as you go through periods of relative normality, but also sadness or anger.



Net, a very diverse “coming out” showing that lupus has many facets, but also each of these facets has a substantially different impact on each individual... and as one of the participants mentioned: “It would have been another day, I might have chosen a very different picture.

Life with lupus is so volatile, so unpredictable. Things can be so different day after day... but my pain and fatigue remain ...”



#### **Session #4 - Clinical trials**

We finished the work day with gathering some information on clinical trials awareness. For this, we split into two groups: on one side, the four participants that had already heard of lupus trials, and on the other, the six that had not.

Those having heard already of trial, heard it from their lupus doctor (2), from their lupus group (1) or from personal research into scientific data (1). None of them actually joined the trial, two because they did not meet the criterion, one “did not consider at all because lupus was stable, but might consider in the future if in a critical situation”, the last one just wanted to get information to understand, but did not consider joining. Factors that would make them consider are the need to help better their own health condition, the absence of response to “generic treatment”, and the geographic proximity.

The group that had not heard of clinical trials in their country yet considers it is their doctor’s job to inform them. They mention that in deciding to join, the key factors would be the risks and collateral effects, the likelihood to improve their condition, and the fact this would be their “last chance”. They would seek advice from their doctor as key element in decision making.

My Rheumatologist:	75%
LUPUS EUROPE web:	40%
Another Rheumatologist:	37%
My National Lupus Group:	34%
A Poster in my hospital:	21%
Another patient I know:	19%
Another Doctor:	17%
An article in a newspaper:	15%
Someone on a Forum:	2%
A Pharma Company web:	1%

We finally got the full group together and asked them how likely it would be that they would talk to their lupus doctor about a clinical trial near their place if they would hear the information from various possible sources. For each, they voted individually from definitely not (to which we attached a 0% value) to definitely yes (to which we attached a 95% value). We attached 5% to “probably not”, 30% to unsure and 67% to “probably yes”. The aggregate results are shown in the next

table. This clearly shows that the likelihood to engage a conversation is the highest when the proposal comes from their own rheumatologist (75%), the next best options being LUPUS EUROPE, a national lupus group or another rheumatologist (all roughly equal at 37% - half the likelihood of own doctor). Posters, patient discussions, articles, other doctors are all again half as effective. Forums or pharma web are negligible. This, in our view shows the critical role that treating rheumatologists and patient groups have to play in the dissemination of information on clinical trials, leading to a discussion on joining, the first step in beefing up participation.



After such great work, the group walked into town for dinner, which turned out to be quite the experience, since there was a Gay Pride Parade taking place and thus the entire City Centre was one big party and all the beautiful old buildings were lit up in rainbow colours.

**SUNDAY MARCH 13**

**Session #5 – My messages:**

In our first session on Sunday, we asked participants what message, and to whom, they would like to send. If they had an opportunity to speak to a particular group, which group would they select, and what would they say...



In a first phase, participants listed 7 different possible audiences they would like to talk to. They then voted to identify the top three which came out as “other young people living with lupus”; “everyone I know” and “non rheuma doctors/GP’s”. Just after these, came “my boyfriend/partner” then my parents.



We then asked participants, using phylacteries shaped post-its to “raise their voice”, writing in very few words what their key message would be for that group. Here is the outcome of that exercise:

**My message to “Everyone I know”** : The first issue raised is that of lack of understanding or awareness: “not every disability is visible”; “I want to be listened

and understood”; “some days could be hard, so try to understand - not downgrading, pity, questioning or judging that I am lazy”; “Be aware of lupus : sunlight is not good for me, never...”; “Although I don’t always have enough energy to meet up, it does not mean I don’t want to...” or “If I say that I am in pain, I am in pain, no matter what you think...”. Paradoxically, the second one appears just at the opposite, wanting to be treated normally: “stop looking at me as if I am sick”; “I am just a normal human with a little special life”; “thank you for treating me normally”; “it’s not a big deal”. The 3<sup>rd</sup> key element raised is one of thanking and reassurance: “your support and understanding is very important to us”, “Parents: It’s OK. I love you” ...



When discussing this outcome with the group, the notion of “balance” appears to be the key: What young people with lupus look for is to be understood, and benefit from awareness, but then not being locked in their disease by their friends and family. Their life is not lupus, but lupus is part of their life. They are grateful that people show interest for their condition... and grateful that people then let them live their life, while being available in difficult times, and understanding their difficulties.

**My key message to “Non-lupus doctors”**: All messages to non-lupus doctors centre around three items :  
 1. The need for doctors to be better retrained (try to be more informed about the disease; study more about lupus – it’s fun), 2. The need to be listened to more (take me seriously, be open minded, listen to your patient, understand me properly), and 3. The need to come up with the right answer (Stop assuming - run the test; Don’ interpret what you want; “lupus” is not always the right answer to my symptoms; I need you to consider MY situation, when I come with a headache, look into it.)

There was a very broad consensus that once you have lupus, your GP blames lupus as a generic answer to any of the health problems that you discuss, leaving the young patient without needed treatment or referring him to the lupus expert, that in turn might send them back to the GP... IN some instances, GP's refuse to acknowledge symptoms of their patients (fatigue or pain), as they cannot objectivate them through observations or measures.

**My message to "Other young people with lupus":** This is by far the topic that collected most individual statements, with 25 statements made in total, and an amazing commonality of views. 10 statements were direct encouragements (Don't be afraid! Don't give up! You are not alone. This is not a life sentence. It sucks, but it's getting better. Remain positive. Don't let lupus hold you back, you can do anything), and 6



others directly related to social life, whether with people with lupus or other friends (together we are strong; have fun with friends, family and your partner; try to know people with lupus; do not isolate yourself; if you lose a friend because you have SLE, that's OK). Finally, several statements referred to self-care and to support (First of all, you have to want to help yourself, and look for the ways to do it; You know your body; don't be afraid of your own body; know your limitations but don't feel limited; always ask for the care you need; your

doctor can be wrong, see a specialist; medical care is available and research is ongoing).

In the debrief, the psycho-social aspect of lupus came very strong. Young people's message is not about the disease activity, the adherence to treatment, the side effects of cortisone or any other "technicality", it is first and foremost about life, being part of the group, building friendship, remaining positive, going out, being alive. Even those aspects that are closer to the disease activity itself, i.e. the impact on the body, are approached as "knowing and not being afraid of your body" rather than a descriptive of possible symptoms or treatments. This outcome was not a surprise, as it matches the general view of young people being more focused on friendship and social aspects, but the magnitude, totally eluding the medical aspects of lupus was definitely unexpected.

**My message to "My partner":** Eight of our participants had a partner, boyfriend or girlfriend. All of them posted at least one message on the "My partner" flipchart. Interestingly, while four posted a "Thank you" for the care and/or the support, the other half used the word "Sorry", as if they had done something wrong, or felt guilty of having lupus (sorry if I can't do everything, sorry, I don't want to ruin your life, ...). Next to this, two participants expressed the need for "space" (give me space, you don't need to take care of me), while two others asked for more understanding (take my fatigue seriously; I AM always doing MY best).

### **Session #6 – Meet with the Doctor:**

In the next session, we had the great pleasure of welcoming professor Frederic Houssiau, Chair of the European Lupus Society, and leader of the Lupus Nephritis network. Participants could raise any questions they had in mind to Professor Houssiau, and received clear answers coming from this undisputed expert. While we do not want to elaborate here on the answers received, the topics raised were as follows: First came pregnancy and maternity as a whole, then questions around pain management (including medication, pain centre, medical marijuana); fatigue; the impact of food (food supplements, food as alternative medicine, things to do or avoid...); the side effects of Cortisone and Plaquenil, and the specific impact of lupus on kidneys (medication, long term risks, transplantation, ...). Finally, the topic of quality of information on internet, fake news, horror stories was also discussed.



### **Session #7 – What next?**

The last topic of our workshop was about Lupus Youth, and their interaction with LUPUS EUROPE or national groups.

All participants were enthusiastic about what they had lived during the workshop. They felt it sad that this was the only youth panel, and expressed that “there was more to do” on many of the topics addressed, so they would all very much like to come back 😊 Having week ends on a theme, with discussions and information would be great) ...



We then addressed the question of Lupus Youth groups. Participants felt that their local organizations were not appealing to young people. They are outdated and too many of their members are “old” resulting in young people not feeling included or energized. Two countries only have active youth groups in some locations. In other places young people join local teams that meet from time to time. As a positive of these local meetings, they mention their mere existence (I can decide to go, it is there), and the non-committed aspects (you decide if you go or skip, even last minute). As key negative, the fact

that people are older, and they can’t relate to them. They would much prefer having active youth groups and feel LUPUS EUROPE should help local groups create those.



We probed how to define “youth”. Where national groups exist, they differ in their inclusion criterion. It typically starts at 18, but with an opening in various countries for people as from 16. This opening was considered important, to avoid a period of isolation when young girls in particular get started with their “young adult social life”. The issue being one of legal framework, as 16-18 years old need to be treated as minors, which impacts organization of events, consent, insurance, ... The upper limit varies much more, with UK defining 26 as the upper limit of their youth group, Italy, Netherlands going for 30, PARE putting the limit at 35. Our participants were selected on an 18 to 28 criterion. The consensus went that from around 30, you start to have another lifestyle, so the group concluded that the target age segment should be 18-30, with an opening to 16-18, and a “definitely out” age of 35 (i.e. accepting that to ease transition, some people might stay a bit beyond 30, particularly those leading the group bringing their experience, but that nobody should be more than 35).



If the group is to be defined with a strict age limit, it also means that its leaders have to be within the limit. Yet, the willingness to commit to specific responsibilities is a big issue. Participants much preferred being involved in “projects”, with time flexibility to manage into an agenda, no obligations, and visible results. They are concerned that taking responsibility for a group could conflict with other priorities (or make them feel guilty if they prioritize other things). It looks too much like a “job”, that requires time and efforts. They have no attraction to becoming “Chair of lupus youth”, focusing rather on “what they want to do” than on titles.



They also feel like the possibility to “escape lupus” is key (“Some days, I don’t want’ to have obligations related to lupus”). The consequence of this is that they rather join less organized structures than a formal youth group (such as Facebook, WhatsApp or Instagram), and smaller structures (five or six people acting as a “group of

friends”) than an organization. Yet, they would love these informal structures to be supported by national groups and LUPUS EUROPE that could provide sharing of best practices, ideas, experience, knowledge or content, and trigger opportunities for them to meet.

They also feel that content “appropriate to young people” should be offered via web. This is more visual, like short answers to questions in the format of 120 seconds videos, blog messages, social media posts from answers to simple questions from doctors, ... Being short is key, a story should not be more than a few paragraphs. Virtual meetings could also be nice, like meeting with a doctor or hearing what others do in a web conference.



The notion of meeting face to face at national or European level is very appealing. Germany and Italy organize such meetings, which are funded by the national organizations. They would very much like to see the same happening in other countries or at European level, but recognize funding is an issue...



Net, the conclusion is that while it would be great to connect young people with lupus across Europe, this should rather be a social media group, with opportunities to do more at individual level. Events could be organized for youth, with their help, but without a structure that makes them feel trapped into a realm of obligations. “Ask me small things and I will manage, but don’t get me in a structure...”

The group then decides to get started, joining the LUPUS EUROPE Facebook group, and creating their own private Facebook group. They

exchanged email addresses, and we know that at this point several of them are effectively in contact regularly.

The workshop concluded with an expedited lunch, allowing most of the group members to rush out for a visit together to the city centre prior to taking their flights or trains back home... Somehow already practicing their model of “LUPUS EUROPE youth group” ...

Alain H. Cornet