



# Our Top Takeaways from EULAR 2021

Every year, thousands of rheumatologists, health care professionals, researchers and patients meet at the European League Against Rheumatism Congress! EULAR 2021 was held online and ran from the 2<sup>nd</sup> to the 5<sup>th</sup> of June. It was an incredible Congress, with lots of interesting sessions and so many things to learn!

The LUPUS EUROPE Board and several of our PAN members attended EULAR 2021 and watched the sessions with great interest! We wanted to take this opportunity to share our top takeaways from EULAR 2021. A few members of our Board and PAN have made their own, separate "Top Takeaways from EULAR 2021" so they could share what they learned with you all and which sessions they would put in their "Top Three" or "Top Ten".

EULAR 2021 may have ended, but you can still register and access the entirety of the scientific programme and presentations online. To register, go to

<https://congress.eular.org/registration.cfm>

Registration costs €35 for patients.

By registering you will be able to watch all presentations, until July 4<sup>th</sup>

# How patients engage in research through the ERN ReCONNET

- Look for Presentation ID: 3502 – Examples of patient involvement and engagement in research – Ana Viera





**Ms. Ana Viera**

Improving collaborative research and patients' participation in health decision-making

Examples of patient involvement and engagement in research

Involvement of patients in ERN ReCONNET: A successful initiative raising patients' leadership at European level



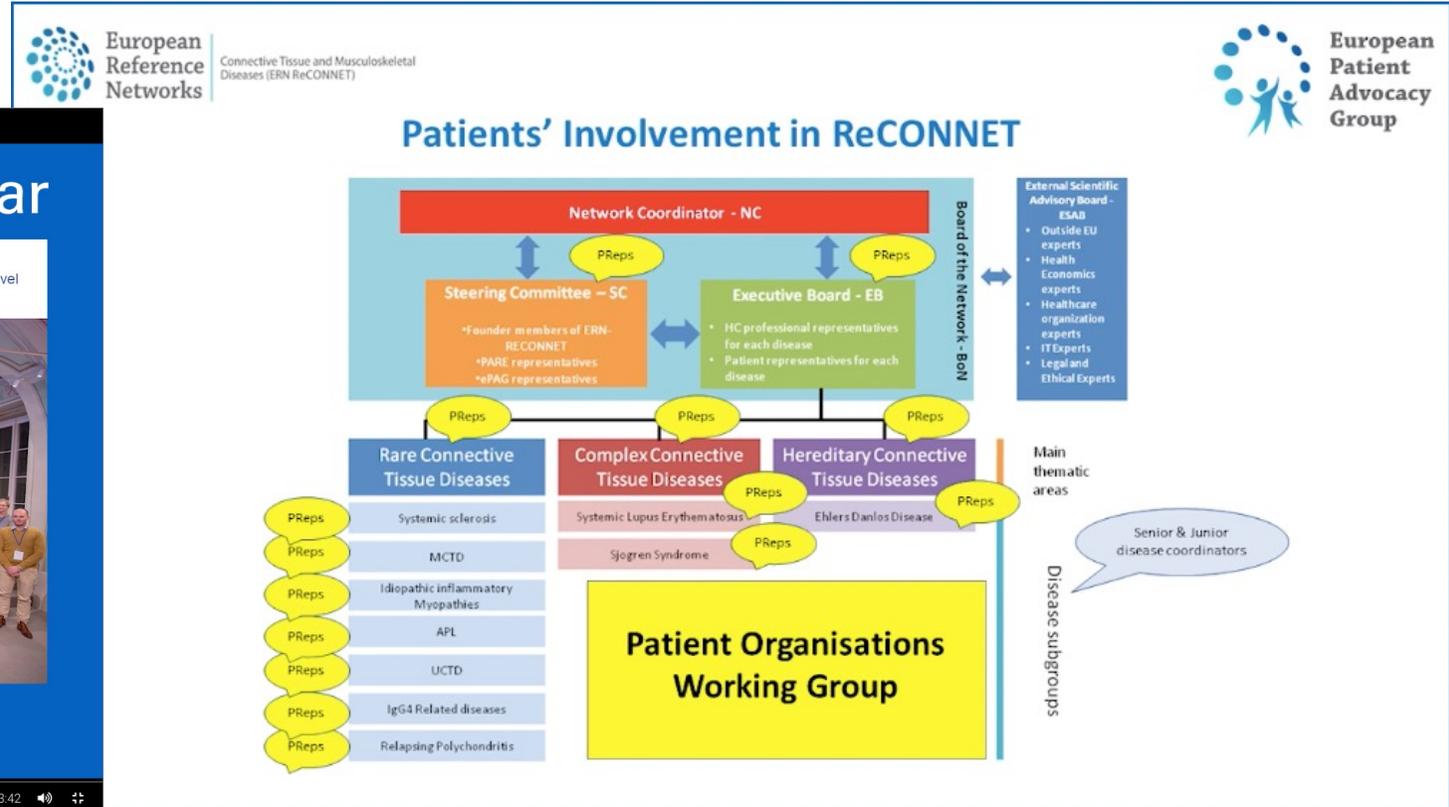
European Reference Network for rare or low prevalence complex diseases

Network Connective Tissue and Musculoskeletal Diseases (ERN ReCONNET)



European Patient Advocacy Group

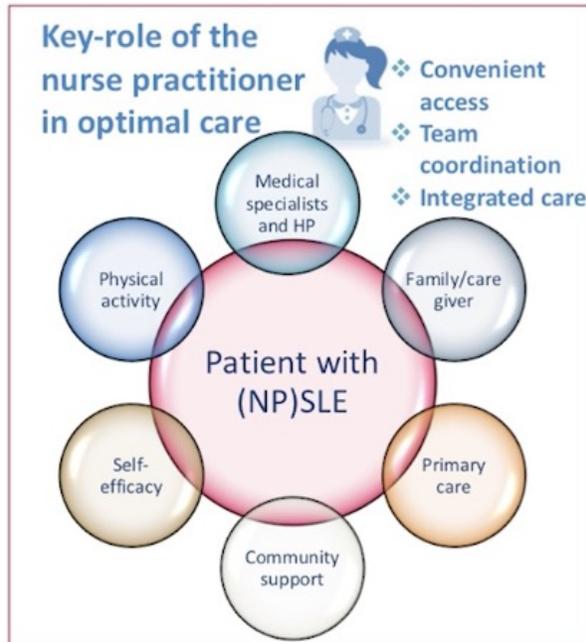




# The importance of the lupus nurse

- Look for Presentation ID 3743 - The role of HPRs as patients' advocates - T.P.M. Vliet Vlieland

## Advocacy on the role of the ANP



## Advocacy on the role of the ANP in care for people with SLE



LUMC Leiden University Medical Center

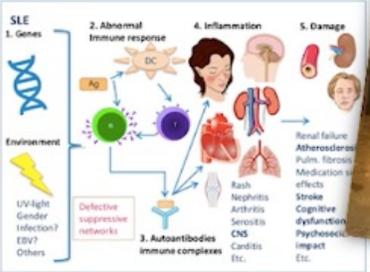
L.J.J. Beart-van de Voorde<sup>1</sup>, R.C. Monahan<sup>1</sup>, G.M. Steunou<sup>1</sup>  
<sup>1</sup> Department of Rheumatology

Changing healthcare and the role of the NP/APN – 394  
 27<sup>th</sup> August 2018  
 Parallel session round 3, 14:30 – 15:30h  
 T.M.J. Huizinga<sup>1</sup>, A.A. Kaptein<sup>2</sup>  
<sup>1</sup> Department of Rheumatology, <sup>2</sup> Department of General Practice

**Advanced nursing care for people with systemic lupus erythematosus (SLE) and neuro-psychiatric symptoms**

**The LUMC NPSLE-clinic**

SLE is an autoimmune disease in which the immune system can attack cells, tissues and organs including the central nervous system (CNS). The LUMC is a tertiary referral center for people suffering from SLE and neuro-psychiatric (NP) symptoms (NPSLE). Since 2007 a medical multidisciplinary team (neurologist, rheumatologist, vascular internist, psychiatrist, neuropsychologist) and an advanced nurse practitioner have been working together in the care for people with SLE and neuro-psychiatric symptoms. This collaboration concerns a 1-day diagnostic program and structured team-meetings resulting in diagnosis and treatment advice based on the assumed etiology of the NP symptoms. Besides the 1-day diagnostic pathway the team-goal is to increase the understanding of NPSLE and improve patient-care.



**SLE Pathogenesis:**

1. Genes
2. Abnormal immune response
3. Autoantibodies immune complexes
4. Inflammation
5. Damage

**Environmental factors:** UV-light, Gender, Infection?, EBV?, Others

**Defective suppressive networks**

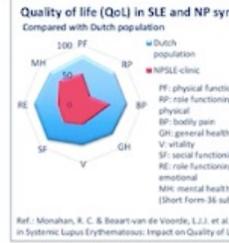
**Renal failure:** Atherosclerosis, Pulm. fibrosis, Medication side effects

**Rash:** Nephritis, Arthritis, Serositis, CNS, Carditis, Etc.

**Other symptoms:** Stroke, Cognitive dysfunction, Psychosocial impact, Etc.

**Quality of life (QoL) in SLE and NP symptoms**

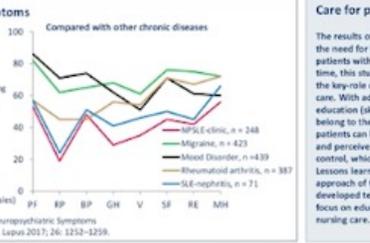
Compared with Dutch population



Legend:  
 - Dutch population  
 - NPSLE-clinic  
 - MH: mental health  
 - PF: physical functioning  
 - RP: role functioning, physical  
 - BP: bodily pain  
 - GH: general health  
 - V: vitality  
 - SF: social functioning  
 - RE: role functioning, emotional  
 - MH: mental health (Short form-36 subscales)

**Quality of life (QoL) in SLE and NP symptoms**

Compared with other chronic diseases

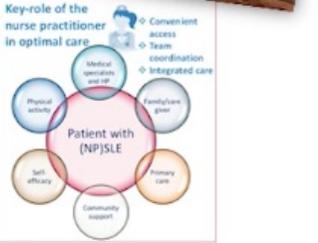


Legend:  
 - NPSLE-clinic, n = 248  
 - Migraine, n = 423  
 - Mixed Disorder, n = 439  
 - Rheumatoid arthritis, n = 387  
 - SLE-nephritis, n = 71

**Care for people with (NPS)LE**

The results of our QoL study illustrate the need for biopsychosocial care in patients with (NPS)LE and at the same time, this study raises the awareness of the key-role of the nurse in optimal care. With adequate support and education (skills that pre-eminently belong to the domain of nurses) patients can be more actively involved and perceive an increased sense of control, which is beneficial for QoL. Lessons learned from our medical approach of the last 11 years, we have developed team-care which includes focus on educational and supportive nursing care.

**Key-role of the nurse practitioner in optimal care**



**Patient with (NP)SLE**

- Physical activity
- Self-efficacy
- Community support
- Primary care
- Family/care giver
- Convenient access
- Team coordination
- Integrated care

# Doctor-Patient communication about sexuality and intimacy

- Look for Presentation ID: 3521 How to communicate about intimacy with my patients - Felice Rivellesse

## Do we discuss sexual health?

### Sexual Health, Intimacy and Rheumatology Practices

Julie Schwartzman-Morris<sup>1</sup>, Arianna Leo<sup>2</sup> and Preeya Nandkumar<sup>2</sup>

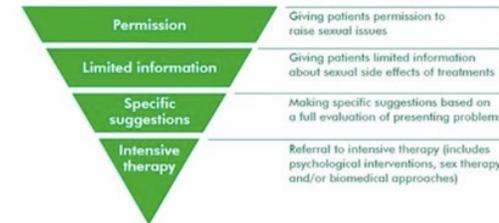
<sup>1</sup>Division of Rheumatology, Northwell Health, Great Neck, NY, <sup>2</sup>Division of Rheumatology, Northwell Health, Great Neck

50 Rheumatologists and health professionals in rheumatology were interviewed:

- **48%** reported that they **discuss the impact of a patient's disease on their sexuality "sometimes"** and 40% **"never"**
- **Lack of skills/knowledge** about sexual health, patient **embarrassment**, patient **age**, while **lack of time and privacy** as barriers
- **66% of HCPs agree or strongly agree that sexual health issues are relevant to rheumatology practice.**

## More specific training?

### PLISSIT model



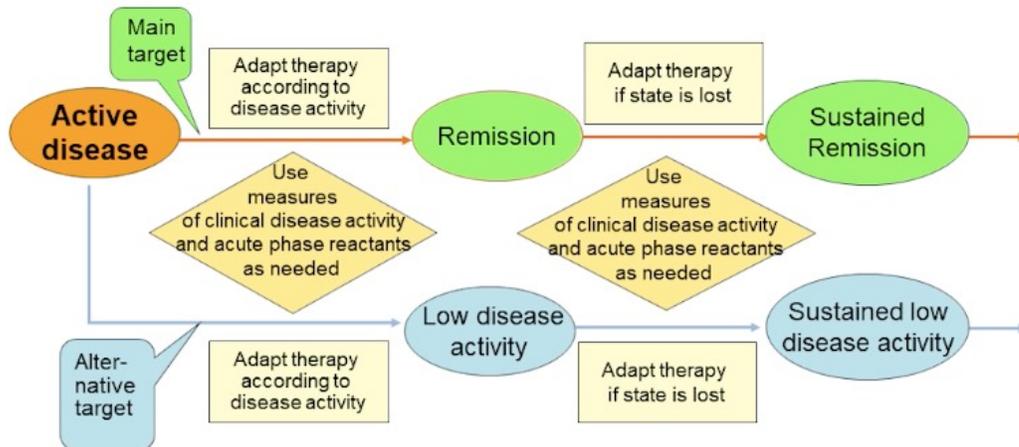
1. Permission: an open ended questions such as "Is there anything about your sexual health you'd like to discuss?"
2. Limited Information: the provider can offer targeted information, including potential causes of the symptoms
3. Specific Suggestions: differential diagnosis offered, with specific suggestions for how to begin addressing the problem.
4. Intensive Therapy: If necessary, a referral can be made to a sexual health specialist

Points 2 and 3 will also require specific knowledge: additional training could be useful !

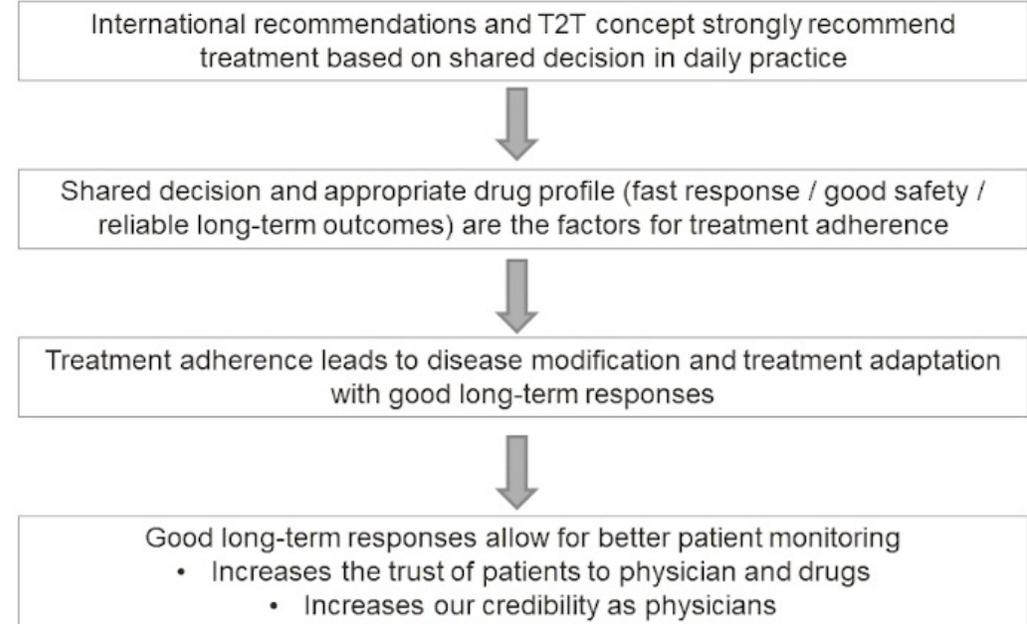
# Managing different expectations towards treatment outcomes

Look for Presentation ID 3515: Adherence and belief - Xenofon Baraliakos

## How do physicians tailor their treatment decision?



## Summary



# Cardio-Vascular risk and recommendations for SLE

- Look for Presentation ID 3916: Recommendations for cardiovascular risk management in Rheumatic and Musculoskeletal Diseases (including SLE and the antiphospholipid syndrome) - M.T. Nurmohamed

## Overarching Principles



- Clinicians should be aware of increased CVD risk & reduction of disease activity is likely to lessen cardiovascular risk.
- Rheumatologists are responsible for CVD risk assessment and management in collaboration with primary care providers, internists or cardiologists and other healthcare providers.
- All individuals should get regular CVD risk factor screening. Risk stratification should include screening and strict control of cardiovascular risk factors.
- CVD risk assessment is recommended within six months of diagnosis.
- Patient education and counselling on CVD risk, treatment adherence, and lifestyle modifications are important in the management of CVD risk.

## Conclusions & Take home messages



- Current increased CVD risks in SLE and gout but also in vasculitis and other connective tissue disorders.
- Every patient qualifies for cardiovascular disease risk management.
- Aimed at efficient reduction of disease activity.
- Optimizing CV risk factors.
- Cardiovascular risk management often poorly implemented.
- Pan-European recommendations facilitate uptake of CV risk management in daily clinical practice.

## GR2 multicentric prospective French study's results: damage but not remission at first trimester predicts adverse pregnancy outcome in lupus pregnancies.

*Maddalena Larosa et al OP0295*

### Lupus and pregnancy over decades

Pregnancy contraindicated in SLE



considering it not as a contraindication but as an indicator of high risk for flares and adverse pregnancy outcomes (APOs)



progressive decline in these risks, although higher than in the general population<sup>1</sup>

Both EULAR<sup>2</sup> and ACR 2020 Guidelines<sup>3</sup> recommended that women to be treated with hydroxychloroquine during pregnancy and to plan pregnancy for periods when their SLE is quiescent, in remission, or in a lupus low disease activity state (LLDAS)

1. Nishiura H, et al. Ann Intern Med. 2019;171(3):194. 2. Andreoli L, et al. Ann Rheum Dis 2017. 3. Sammaritano LR, et al. Arthritis Rheumatol. 2020;72(4):529-56.

### Aim of the study

To determine the 1<sup>st</sup> trimester risk factors for adverse pregnancy

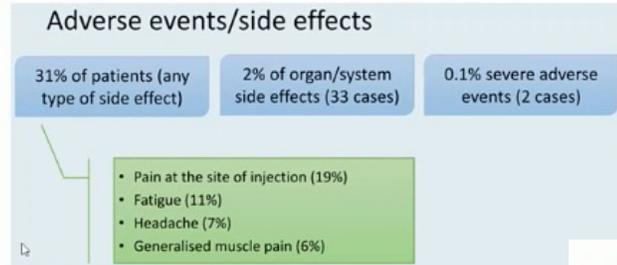
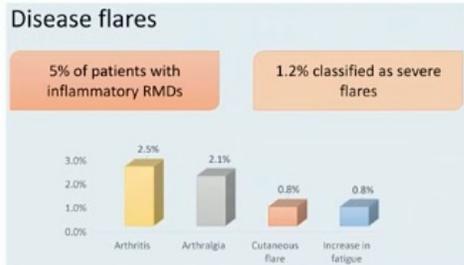
outcome (APO) in a cohort of SLE pregnant patients

### Conclusions

- Similarly to PROMISSE, we confirmed that positive LAC predicts APO
- For the first time we found that the extent of chronic irreversible, damage also predicts APO
- Neither remission nor LLDAS had an observable effect in this cohort of lupus patients treated with hydroxychloroquine (98.3%) and with stable, well-controlled SLE

# Latest update from COVAX registry

- Look for Presentation ID LB0002: COVID-19 vaccine safety in patients with rheumatic and musculoskeletal disease - Pedro M Machado

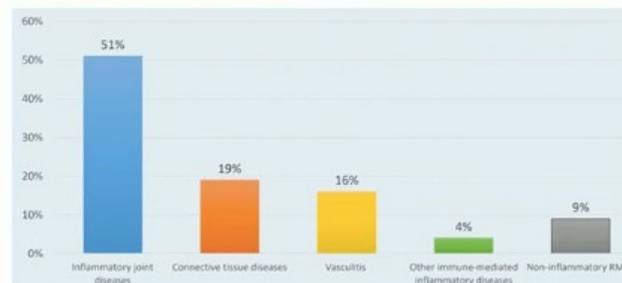
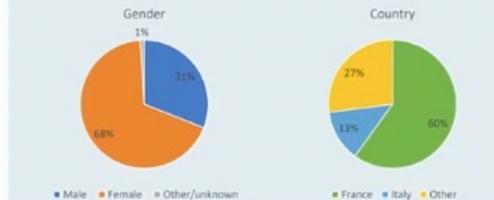


## Conclusion

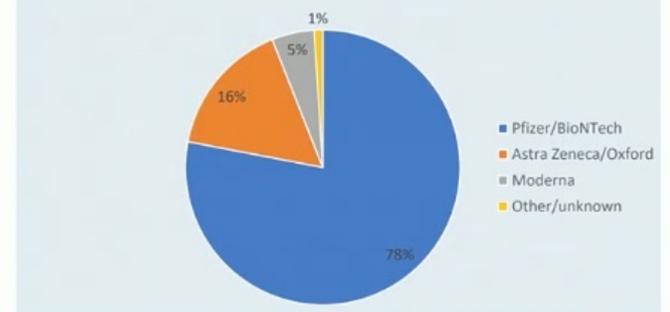
- The safety profiles for COVID-19 vaccines in RMD patients was reassuring.
- Most adverse events were the same as in the general population
  - Non-serious short term local and systemic symptoms
- Overwhelming majority of patients tolerated their vaccination well with rare reports of inflammatory RMD flare and very rare reports of severe adverse events
- These initial findings should provide reassurance to rheumatologists and vaccine recipients, and promote confidence in COVID-19 vaccine safety in RMD patients, particularly those with inflammatory RMDs and/or taking immunomodulatory treatments.

## Results: demographics

• N = 1519; Mean age 63 years (SD 16; 15 to 97 years); 28 countries



## Vaccines administered



## T2T – Remission in SLE

- Look for Presentation ID 6921: Towards a common definition of remission in SLE: the DORIS project - **Ronald van Vollenhoven**

### Objective



- To arrive at a broadly supported, valid and feasible definition of remission in SLE for use in clinical care, education, and research including clinical trials.

### Conclusions



- The DORIS Task Force has arrived at a broadly supported and feasible definition of remission in SLE with excellent face, content, construct and criterion validity
- This definition will be useful as:
  - Aspirational target in clinical care
  - Concept in education
  - Outcome in observational studies and clinical trials

Look for Presentation ID 6924: Is remission achievement possible with the today's drugs? - Chiara Tani

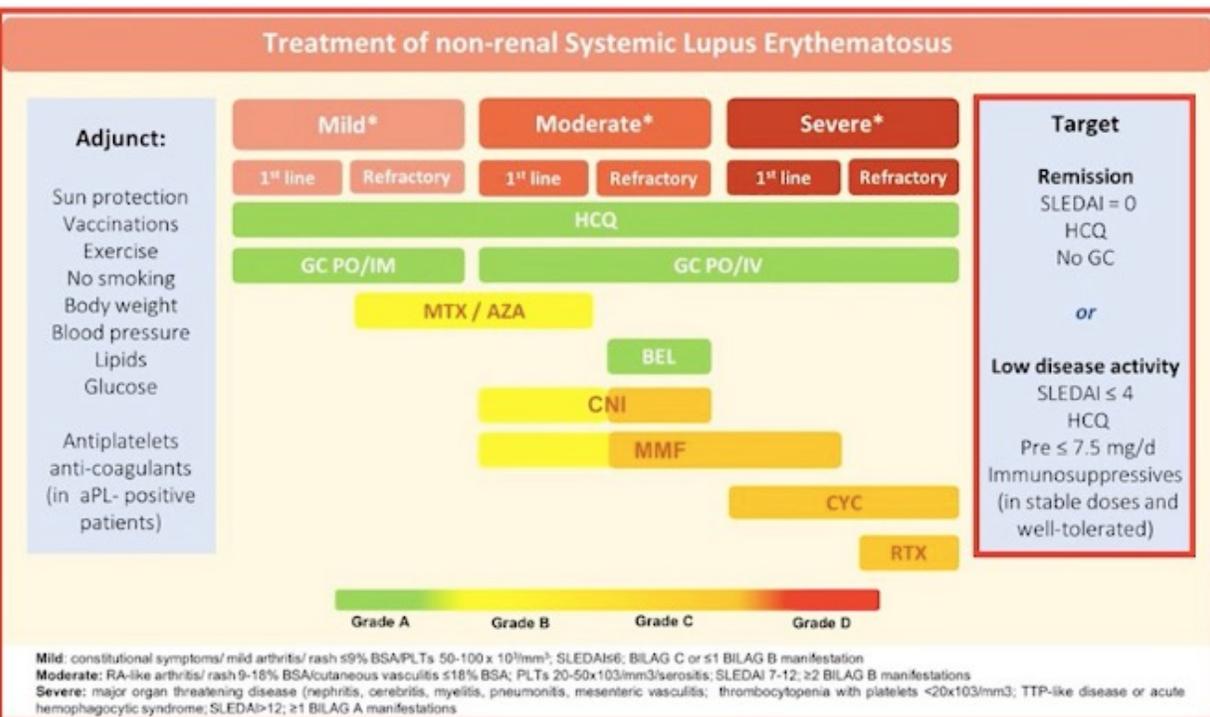
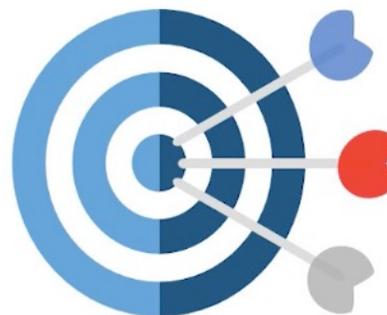
## CONCLUSIONS

- Remission is an achievable target in the majority of SLE patients
- Prolonged remission, especially off treatment, is less frequent
- Durable remission is prevented in a significant proportion of patients by recurrent flares, persistent disease activity or an inability to taper GC

## Treatment goals in SLE

## IS THERE FURTHER ROOM FOR IMPROVEMENT?

- YES!
- New, more effective drugs
- Steroid-sparing strategies
- Strategies to prevent poor adherence (HCQ!)
- Patient empowerment
- Equal access to the best standard of care across different countries





# Look for Presentation ID 3517: Patients' education, expectations and outcomes - Heidi A. Zangi

## Targeted aspects in patient education



Roe et al 2020



**EULAR recommendations for patient education for people with inflammatory arthritis**

## A need for

From doctors' provision of information and patients as passive recipients



To patients' involvement in decisions and management of their care



paying attention to health literacy in targeted populations with RMDs



looking at how interventions can be designed to meet expectations and needs from different populations



investigating which content, methods and delivery modalities are best suited to enhance health literacy



how we can ensure patient participation in designing, planning, delivering and evaluation of patient education



# EULAR 2021 My Three Top Learnings

## Treatment of Severe Lupus Nephritis” by Prof Frederic Houssiau

As someone who suffers from LN, and who speaks with other patients with LN, I think it’s important to understand the impact that lupus can have on our kidneys. For many of us being diagnosed with LN comes as a surprise, because we didn’t have any visible symptom and even more of a shock is to know that our LN has progressed very quickly despite treatments. Prof Houssiau starts saying that when someone is diagnosed with LN “He, she loses actually lot of nephrons, and this will impact long term renal function”. This is a real eye-opener. Then he discusses why lupus nephritis is always severe, which is very important to know. More emphasis should be given on this, so we closely monitored our urine and kidneys, we would be wasting valuable time for our kidneys if we don’t.

eular

What is severe nephritis ?

LN is always severe!

Prof. Frédéric A. Houssiau

Treatment of severe lupus nephritis

Kidney injury  
Drug toxicity  
Comorbidities

## “The Lupus Low Disease Activity State” by Prof. Eric Morand

As someone who has had lupus since very young age, this presentation has taught me about focusing on attainable targets in lupus. We wish remission, but this isn't always possible. However, there's also Low Disease Activity State (LLDAS) and this is a valid target. This team of researchers have working on a clear and precise definition of LLDAS. As a patient with a chronic condition, it's important to know what our current treatment will help us to achieve, and what quality of life we can expect as we know that there's no cure.



**Prof. Eric Morand**

**Treating SLE to target: remission or low disease activity?**

—

The Lupus Low Disease Activity State

### 2019 Validated Definition of Lupus Low Disease Activity State - LLDAS

1. SLEDAI-2K  $\leq 4$ , with no activity in major organ systems (renal, CNS, cardiopulmonary, vasculitis, fever) and no haemolytic anaemia or gastrointestinal activity
2. No new features of lupus disease activity compared with the previous assessment (SLEDAI-2K)
3. SELENA-SLEDAI Physician Global Assessment (PGA, scale 0–3)  $\leq 1$
4. Current prednisolone (or equivalent) dose  $\leq 7.5$  mg daily
5. Well-tolerated standard maintenance doses of immunosuppressive drugs and approved biological agents

Franklyn K, et al. Ann Rheum Dis 2016



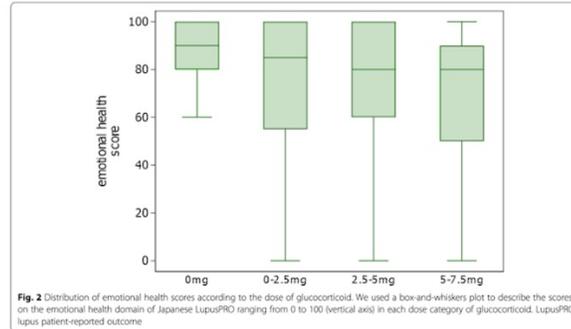


**Prof. Eric Morand**

**Treating SLE to target:  
remission or low disease  
activity?**

The Lupus Low Disease  
Activity State

**In LLDAS, lower glucocorticoid dosing is associated  
with better emotional health**



Miyawaki, Y. et al. *Arthritis Res Ther* 23, 79 (2021).



Also, it was very important to see the emphasis done on steroids withdrawal. We know how good steroids can make us feel at first, the pain relief and extra energy we feel but quickly after we start suffering the side effects such as raised heart beats, the moon face, extra weight, constant hunger, etc. Consultants are aware of the damage, and it's one of their aims to get us off steroids quickly.

## “Stress and Autoimmune Diseases” by Prof Georg Pongratz

It was very interesting and important to understand how stress works in our bodies and the link between stress and autoimmunity. Prof Pongratz discusses the links between these two, how stressful situations such as parents’ divorce can be a trigger and that “stress somehow paves the path for getting an autoimmune disease”. It’s a topic that has always interested me a lot, as in my case, and for many people too, my lupus started after a very stressful event.





**Prof. Georg Pongratz**

**Stress, inflammation & autoimmunity**

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Stress and autoimmune diseases







**Physiological stress reaction - acute**



acute Stressor



Amygdala

↓

sympathetic activity

↓

catecholamines



„fight and flight“ reaction

Hypothalamus

↓

pituitary gland

↓

adrenal gland

↓

cortisol

time

ca. 15 minutes →

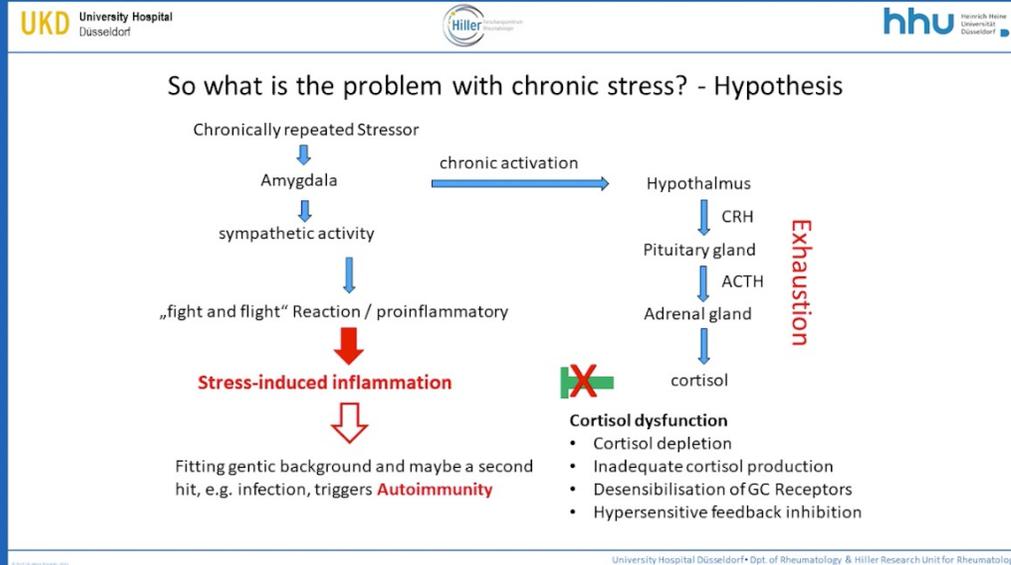
© 2013 Georg Pongratz, PhD  
University Hospital Düsseldorf • Dpt. of Rheumatology & Hiller Research Unit for Rheumatology



**Prof. Georg Pongratz**

**Stress, inflammation & autoimmunity**

Stress and autoimmune diseases



Nowadays, you can quickly see how your joints and muscles start to hurt after some stressful situation, and if you don't manage your stress, it simply gets worse. I believe that more tools for managing stress, which can't be eliminated of our lives, should be given to people with lupus as part of their treatment and for improving their quality of life. Those who run patient support groups and consultants can play a very important role here.

# My top 10 from EULAR 2021

Alain Cornet – June 2021

You can still watch  
all EULAR material  
till July 5 on

<https://www.congress.eular.org/>

# 1. Evidence based tips on diet and RMD



- Nutrition plays a role in inflammation.
- The type of diet you choose matters.
- Limit your salt intake, use more herbs.
- Consume low glycaemic index foods.
- Oily fish and omega-3 are good.
- Show preference for the Mediterranean diet.
- Increase the amount of anti-inflammatory foods, reduce pro-inflammatory diets.
- Coffee in moderation, show preference for (green) tea.
- Important to keep good control of co-existing conditions.
- Maintain an optimal BMI and keep fit.

**Diet is a powerful means of reducing inflammation.**

**The Mediterranean diet** enriched with oily fish and antioxidants should be adopted where possible.

Foods high in omega-3 fatty acids are anti-inflammatory.

**Avoid pro-inflammatory foods, reduce salt & sugary drinks.**

**Avoid anti-inflammatory foods, prefer a diet high in fiber, low in glycaemic index.**

**Coffee & alcohol should be consumed in moderation.**

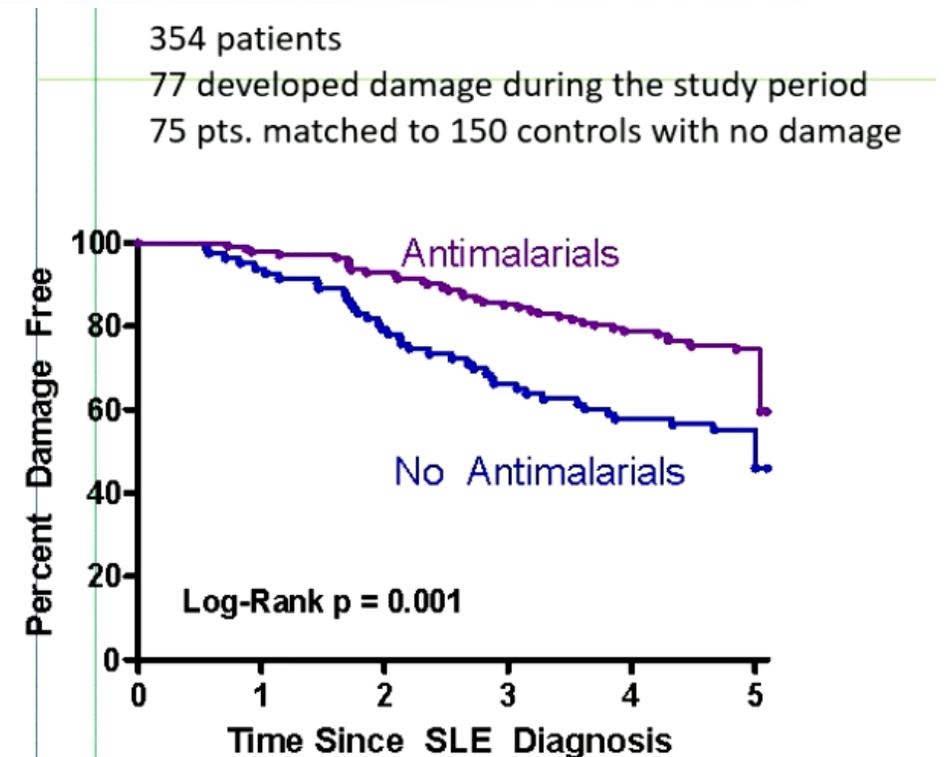
Consider **Vitamin D and other vitamin** supplementation where appropriate.

**Maintain healthy BMI and exercise regularly.**

## 2. Antimalarials adherence reduces Mortality and protect SLE patients for damage accrual

Conclusion: SLE patients adhering to AM therapy had a 71% and 83% lower risk of death than patients who do not adhere or who discontinue AM, respectively.

Antimalarials are protective for damage accrual in SLE patients from the time of diagnosis



### 3. Lupus Clinics deliver much better Quality of care than general (Rheumatology) clinics

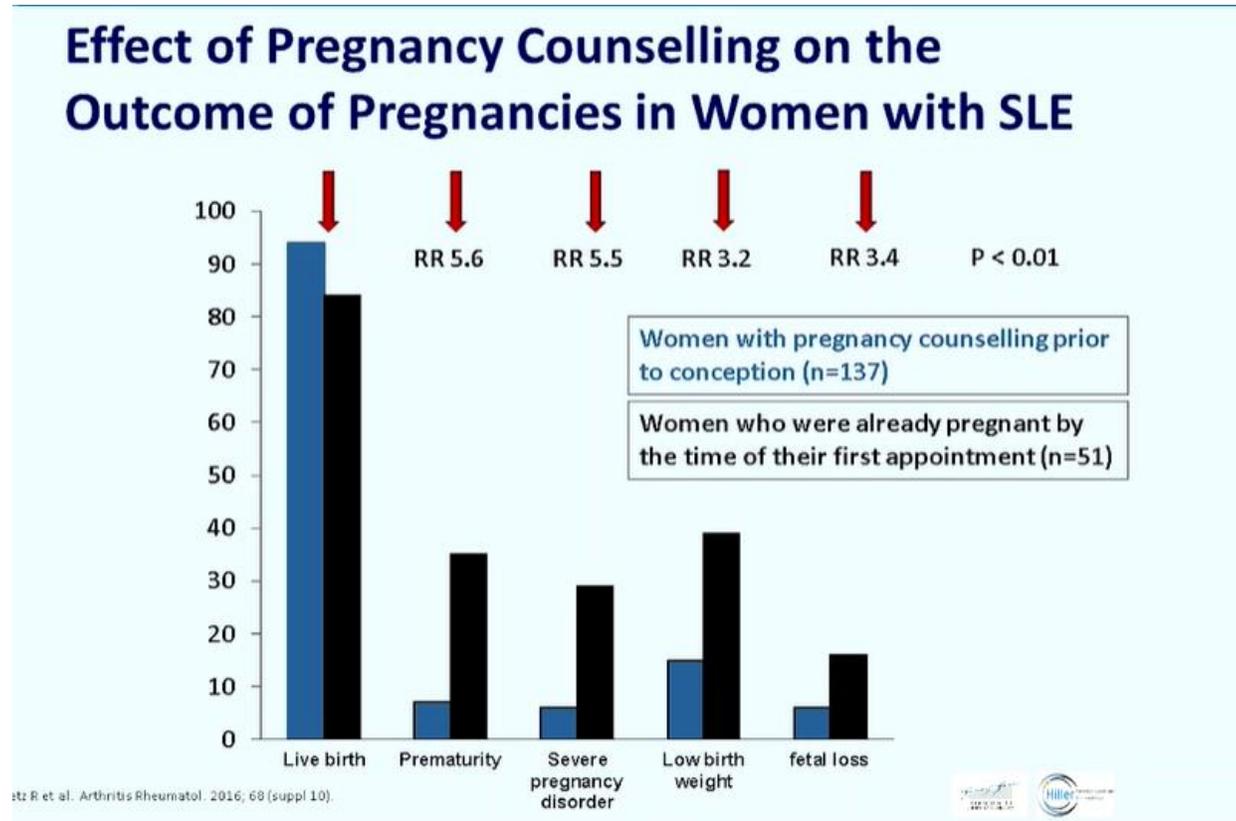
#### MAIN FINDINGS

In a universal healthcare system, patients with systemic lupus erythematosus received higher quality of care in a subspecialty lupus clinic compared with hospital and private general rheumatology clinics.

Table 1: Overall QI performance by clinic setting

QI performance (median [IQR])	LC (n=147)	HC (n=56)	PC (n=55)	p value
EMR only	66.7% [16.9]	52.7% [10.6]	50.0% [18.0]	<0.01
EMR and PSR	73.1% [14.8]	68.1% [11.5]	63.2% [13.4]	<0.01

# 4. Pregnancy counselling BEFORE conception substantially improves pregnancy outcome



## 5. COVID - No specific medication is linked with increased COVID risk

- Safety profiles for COVID-19 vaccines in RMD patients was reassuring
- Most adverse events were the same as in the general population (short-term non-serious symptoms)
- Overwhelming majority of patients tolerated their vaccination well with rare reports of inflammatory RMD flare and very rare reports of severe adverse events
- These initial findings should provide reassurance to rheumatologists and vaccine recipients, and promote confidence in COVID-19 vaccine safety in RMD patients

- Risk factors for hospitalisation/death among people with RMDs largely similar to those without RMDs
  - Older age, male gender and comorbidities
- Importance of controlling disease activity
- Risks of RTX, SSZ, steroids and some immunosuppressants?
  - However, the priority should still be disease control!

Look for : Presentation ID 7105 - The EULAR COVID and COVAX registries- Pedro M Machado

# 6. 40-80% of medical information from consultation is forgotten immediately

"Studies have shown that 40-80% of the medical information patients are told during office visits is forgotten immediately, and nearly half of the information retained is incorrect."

U.S. Agency for Healthcare Research and Quality

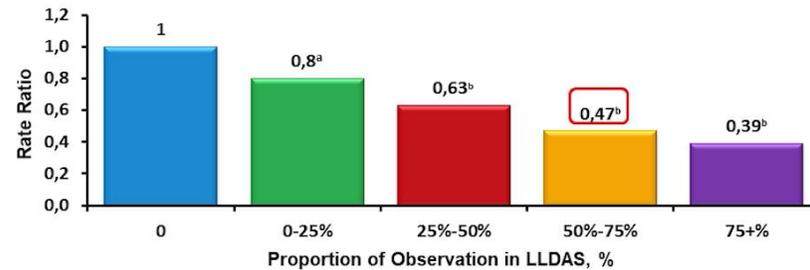
1. Use a caring tone of voice and attitude.
2. Display comfortable body language and make eye contact.
3. Use plain language.
4. Ask the patient to explain back, using their own words.
5. Use non-shaming, open-ended questions.
6. Avoid asking questions that can be answered with a simple yes or no.
7. Emphasize that the responsibility to explain clearly is on you, the provider.
8. If the patient is not able to teach back correctly, explain again and re-check.
9. Use reader-friendly print materials to support learning.
10. Document use of and patient response to teach-back.

<http://www.teachbacktraining.org/home>

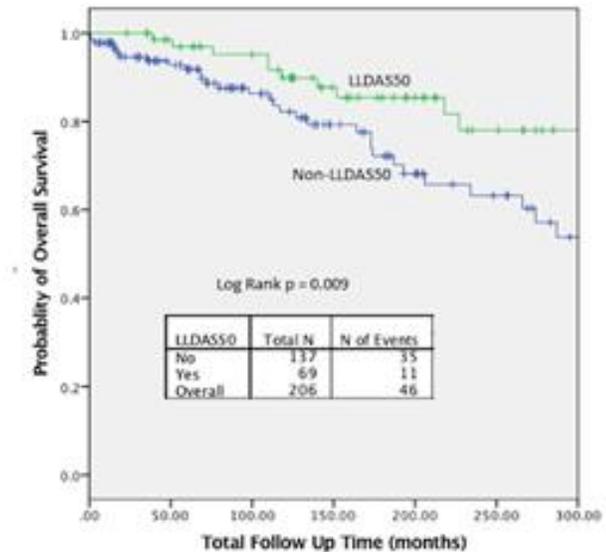
Look for Presentation ID 3657 - Why do we believe in fake news? - Catherine Beauvais?

## 7. LLDAS (Lupus Low Disease Activity Score) is the right target for clinical management and for clinical trials

- Achieving more often LLDAS is linked with lower damage accrual, reduced likelihood of flare, improved Quality of life, reduced mortality

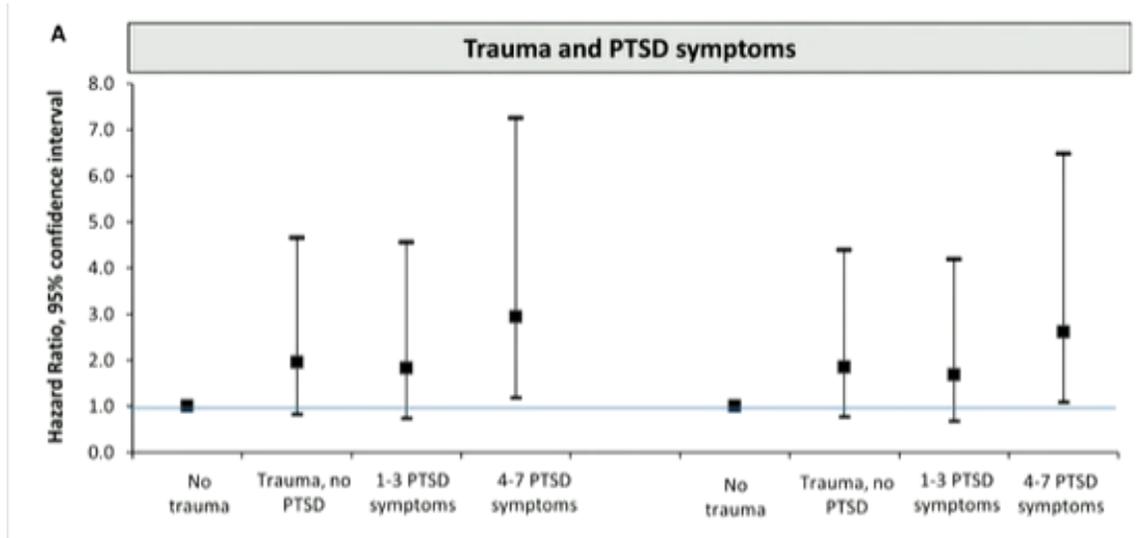


50:50 rule - 50% reduction in damage accrual with 50% of time in LLDAS.



- LLDAS is more discriminant than remission in clinical trials

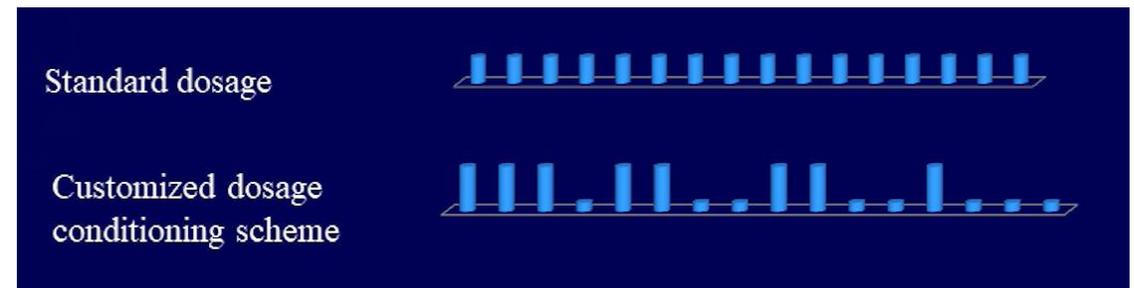
## 8. High Stress / Trauma exposure is associated with almost 3-fold increased SLE risk:



**PTSD was associated with increased SLE risk, HR 2.94 (95% CI 1.19-7.26),  $P < 0.05$ .** Trauma exposure, regardless of PTSD symptoms, was strongly associated with incident SLE (HR 2.83 (95% CI 1.29-6.21),  $P < 0.01$ ).

# 9. Placebo and Nocebo effects

- Reading the leaflet reduces the willingness to take the medication and reduces adherence
- Expecting a side effect (for example because it is talked on facebook) increases its probability of actually happening
- “Conditioning” can help reduce the quantity of medication needed without reducing the effect

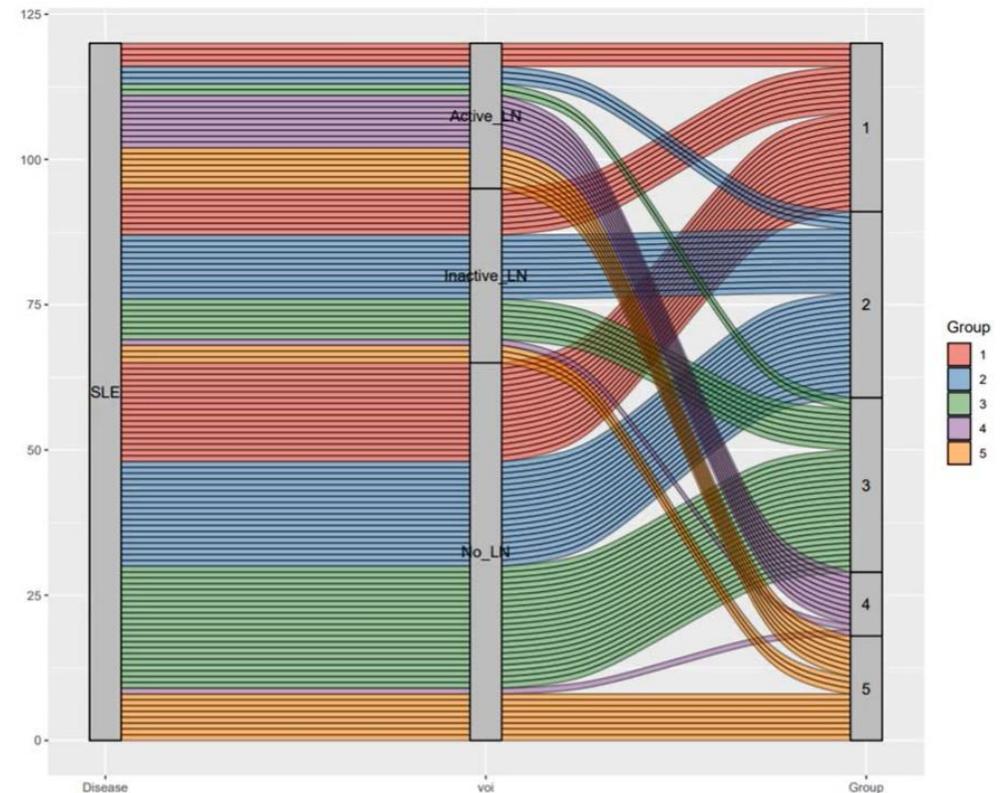


# 10. Reclassifying patients based on biomarkers can lead to Personalised medicine approach

- SLE clinical spectrum encompasses several **distinct molecular endotypes**, each defined by unique pathogenic aberrancies
- SLE molecular endotypes can be utilized to guide **personalized care** and direct **novel compound development**

Look for Presentation ID OP0019 - Defining Systemic Lupus Erythematosus Molecular Taxonomy Through Data-driven Restratification and Identification of Cluster-tailored Drugs for a Personalized Medicine Approach - Panagiotis Garantziotis

Data-driven patients re-stratification independently of their clinical annotation



# 5 “MUST WATCH” Videos for PAN / Patient experts or those that would like to go further

1. It's never lupus - A 15' video recapping what lupus is, clinically, and how some hypothesis on its mechanisms are leading development of treatments - Look for : Presentation ID 7131 - It's never lupus! - Chris Wincup
2. All you need to know about Lupus Low Disease Activity score – Likely the most relevant target for treatment and clinical trials. Look for Presentation ID 6922 - The Lupus Low Disease Activity State - Eric F. Morand
3. A summary of what we know today about Hydroxychloroquine and its effects, including possible side effects : Look for Presentation ID 6889 - Hydroxychloroquine in rheumatic diseases: not only SLE - Thomas Dörner
4. Placebo and Nocebo – If you think you know everything about placebo effect, watch this and be surprised on how much we can trick ourselves positively or negatively. Look for Presentation ID 6977 - Mechanisms, predictors, and interventions to prevent, minimize, or extinguish nocebo effects in pain - Andrea Evers
5. A great and clear explanation on how “deep science” and artificial intelligence can help reclassify lupus and hopefully find faster the treatment that works for each individual : look for Presentation ID OP0019 - Defining Systemic Lupus Erythematosus Molecular Taxonomy Through Data-driven Restratification and Identification of Cluster-tailored Drugs for a Personalized Medicine Approach - Panagiotis Garantziotis