The voice of the patient: how to fill the communication-gap between doctors and patients

Led by Sara Badreh (Lupus Europe) and Jeanette Andersen (Lupus Europe)
Established in 1989

26 national lupus groups:

Between 10- 6,000 members each

Total membership of +30,000

Approx 500,000 diagnosed with lupus in Europe*

Orphanet 2016 –not rare
Lupus Europe engagements

- EULAR Recommendations
  - Comorbidities
  - Lactation on RA and SLE treatment
  - Women's Health Issues

- European Consortia
  - FOREUM
    - REFRACT, DORIS, "When the wolf bites its offspring"
  - EU Horizon 2020
    - United, iManage, ERN ReCONNET

- International Initiatives
  - T2T, DORIS, World Lupus Federation
Lupus Europe activities

The work done in our community:

*LUPUS EUROPE Task Force on Research & Clinical Trials*

**EPF** – WG Access, WG Cross-Border Healthcare, WG PAG Sustainability and more

**EU/IMI** – EUPATI, Precisesads

**PARE/EULAR/ACR** – PAGs, Youth, Task Force, Intl study group and more => LNTN, DORIS, United, Classification/biomarkers, ERN

The work done for our members:

LUPUS EUROPE Convention 2016 – TREATMENT, 2017 – Stress, Pain & Fatigue

Patient Panels

Working to have the patient perspective included in the scientific programme of conferences
Introduction to workshop
Adhering to treatment

- When seeing patients, doctors can sometimes take the “parenting” role, as to say what is the best for the situation without further explanation or elaboration to the patient, to make him or her understand their responsibility in their own disease-related treatment. How do you best explain to the patient the risks involved in not adhering to treatment and the impacts that it might have on their general life situation?
Pregnancy and medications

- When patients are treated with immunosuppressive drugs such as methotrexate it is crucial to prevent the occurrence of unplanned pregnancy due to complications and side effects of the treatment. How do you best communicate with the patient the risks involved in unplanned pregnancy to make both parties agree with full understanding of the situation?
Quality of life

- As educated doctors, prepared to treat and heal, the focus on how to best increase the quality of life for the patient is sometimes skewed towards, what medications that would be the best suitable one with less side effects without consideration of what other needs the patient might have besides medications, in order to increase their quality of life. What might be important for the patient vs. the doctor when it comes down to living their lives to the fullest despite pain and disease activity? Is it the medication with less side effects but slightly decreased self-sufficiency or the medication with a bit risk but that allows less handicap? How do you prioritize?
Expectations

- When treating patients, what is the reasonable expectations on both parties? Who is responsible for what? Does the patient have a right to assume that the doctor “will fix them” or does the doctor have the right to assume that the patient will “help fix themselves”?
- How do you best solve the communication between doctor/patient for minimum misunderstanding regarding the expectations we all have of each other?