Results Of 169 children, 139 (82%) females. Median age at disease onset: 11.4 years (3.4–18), median age at diagnosis: 12 (3.5–19).

20% had history of autoimmune disease in first degree relative.

Therapy at disease onset (first 6 months):
- Hydroxychloroquine: 100%,
- Glucocorticoids: 98%,
- Mycophenolate: 33%,
- Methotrexate: 27%,
- Azathioprine: 16%,
- Cyclophosphamide: 9%,
- Rituximab: 2%.

At last follow up: Glucocorticoids: 37%

Median follow up 48 months (1–195 months), Mortality: 4%, lost to follow up: 19%, active disease at last follow up: 25%.

Conclusions Patients seen at our centre had a significant disease burden with a median SLEDAI score of >20 at presentation.

Upto 1/2 of the study population did not have a malar rash. 38% had renal disease. Fever was seen in 82% and often was the cause for seeking medical opinion. This is a small data set from a tertiary level centre and not representative of the community disease.

References
in hospital and profound long term health consequences. It charts a journey to a more effective model of treatment and self-management. This now sees her largely symptom free, on minimal lupus medication (blood pressure tablets) and leading an active personal and professional lifestyle.

Mary draws from her four decade experience to suggest a model of doctor - patient communication, collaboration and partnership that has implications for improving outcomes and quality of life for all lupus patients.

**Methods**

- Giving the patient a voice. Understanding the powerful psychological benefits with consequential direct and indirect physical benefits for the patient when they are regarded as an “equal partner”, an active as opposed to a passive participant in the treatment journey.
- Importance of information sharing with the patient, the treating immunologist and the general practitioner.
- Understanding that the fluctuating and multi-organ nature of lupus symptoms means that treating obvious presenting symptoms without understanding and treating the underlying auto-immune causes can and does lead to treatment errors and adverse patient outcomes.
- Addressing the whole patient, their physical, mental and emotional wellbeing, and the general hormonal system can greatly reduce ongoing symptoms and acute flares.

**Results**

Improved patient outcomes.

**Conclusions** A more effective model of care.

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**A CASE OF DERMATOMYOSITIS WITH ELEVATED SERUM KL-6 LEVEL ASSOCIATED WITH OVARIAN CANCER**

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**Background and aims** Elevated serum Krebs von den Lungen-6 (KL-6) is a biomarker of interstitial pneumonia and some types of cancers. Because patients with dermatomyositis (DM) may accompany interstitial pneumonia and malignancies, serum KL-6 level has been commonly examined for patients with DM in Japan.

**Methods** A 62-year-old woman developed myalgia in bilateral thighs in November 2014. She was admitted to our hospital in the following month because of progressive bilateral proximal muscle weakness and myalgia, elevated serum creatine kinase (CK: 5569 U/L), and Gottron’s papule. Although muscle biopsy had not been done, the diagnosis as DM was further supported by muscle MRI, electromyogram and skin biopsy. The body CT revealed pelvic mass with ascites, but not interstitial pneumonia.

**Results** Although prednisolone 50 mg/day and intravenous immunoglobulin therapy against progressive muscle weakness including severe dysphagia only showed a partial response, the surgical resection of ovarian mass, identified as ovarian serous adenocarcinoma stage II c, followed by chemotherapy resulted in clinical remission of DM. Serum KL-6 level, as well as CA-125 decreased below the upper normal limit.

**Conclusions** The present case suggests that the measurement of serum KL-6 may be useful in the evaluation of patients with DM.

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**THE ITALIAN SLE SURVEY BY WEB: INVESTIGATING PATIENTS’ UNMET NEEDS WITH ONLINE SURVEY TOOLS**

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**Background and aims** Chronic illness perception and difficulties in everyday life due to disease and medications were explored by the first italian ONLINE SLE SURVEY, designed to assess chronic pain impact and health-care provision quality in Italy.

**Methods** Online questionnaire was created through Qualtrics, setting geographic data, disease duration, age at diagnosis, comorbidity, disability degree, care practices, treatments, subjective incidence and characteristics of pain. SLE patients were advertised by social media. Participation was voluntary and anonymous.

**Results** 550 SLE patients provided complete data; F 94.7%, M 5.3%; mean age 33 y. (14–82 y.); first SLE diagnosis at mean age 29 y.: 84% received SLE diagnosis between 18–42 y.; 36% comorbidity with other (1-6) autoimmune conditions. SLE impact on life is relevant, with specific problems and needs at different disease stage. Stress of life: relevant and worsening illness conditions; frequent relational problems.

**Conclusions** Health-care current model doesn’t allow respect of SLE patients complex needs: most remain dissatisfied, affecting quality of life and doctor-patient concordance. SLE SURVEY highlights importance of competent clinical listening by physicians and capacity to hold patient’s crisis. GRUPO ITALIANO LES – a volunteer patients’ organisation - established ONLINE SLE SURVEY practice to explore current facts, development of patients’ needs, and set social-health policies.