

Below, you will find two questionnaires. The first sheet aims at understanding your organ involvement, Please do only tick „Yes“ if you are sure that you have (or had) this organ problem yourself. Likewise, we would ask you to only tick specific autoantibodies when those have definitely been tested positive for you.

My organ involvement

Skin Yes NOT SURE NO I do not wish to answer this

Joints Yes NOT SURE NO I do not wish to answer this

Kidney Yes NOT SURE NO I do not wish to answer this

CNS/Brain Yes NOT SURE NO I do not wish to answer this

Blood/Bone marrow Yes NOT SURE NO I do not wish to answer this

Anti-phospholipid syndrome Yes NOT SURE NO I do not wish to answer this

Fibromyalgia Yes NOT SURE NO I do not wish to answer this

My Autoantibodies

ANA Yes NOT SURE NO I do not wish to answer this

Anti-(ds)DNA Yes NOT SURE NO I do not wish to answer this

Anti-Ro Yes NOT SURE NO I do not wish to answer this

Anti-La Yes NOT SURE NO I do not wish to answer this

Anti-Sm Yes NOT SURE NO I do not wish to answer this

Anti-U1RNP Yes NOT SURE NO I do not wish to answer this

Anti-Cardiolipin Yes NOT SURE NO I do not wish to answer this

Central to the main research question of the project is the following second questionnaire: For the symptoms, we would ask you to tick „Yes“ or „No“ for now, for the first year after your SLE diagnosis, and for the time before the diagnosis of SLE, for each specific symptom or problem. The last page is for symptoms that are not yet listed. In case you should run out of space, we are grateful for additional items on any kind of paper.

Symptom	Before diagnosis	1st year of SLE	Now
Blue/White fingers	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Fatigue	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Fever	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Hair loss	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Joint pain	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Muscle pain	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Pain when breathing	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Pneumonia	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Shortness of breath	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Skin bleeding	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Skin rashes	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Sun hypersensitivity	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Swollen legs, edema	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Thrombosis	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>

Other symptoms

Symptom

Before diagnosis

1st year of SLE

Now

_____ YES NO

YES NO

YES NO

_____ YES NO

YES NO

YES NO

_____ YES NO

YES NO

YES NO

_____ YES NO

YES NO

YES NO

_____ YES NO

YES NO

YES NO

_____ YES NO

YES NO

YES NO

_____ YES NO

YES NO

YES NO

_____ YES NO

YES NO

YES NO

_____ YES NO

YES NO

YES NO

This completes the questionnaire. Many thanks!