Appendix 1

Systemic Lupus Erythematosus Quality of Life Questionnaire

Thank you for completing this questionnaire that allows us know more about the day-to-day problems that affect SLE patients. This will help us to understand lupus patients better and perhaps come up with ways to improve the overall treatment of the disease.

For each item, please circle one number that best demonstrates its importance in your life. Please do not ask anyone to help you answer the questions because you are the best person to know your disease and how it affects you. There are no right or wrong answers.

Please use this scale to answer the following question: 1=not difficult at all, 2=hardly difficult, 3=somewhat difficult, 4=moderately difficult, 5=quite difficult, 6=very difficult, 7=extremely difficult.

How difficult has each of these activities been in the last week as a result of your SLE?

1	Walking outdoors on level ground.	1..2..3..4..5..6..7
2	Shopping.	1..2..3..4..5..6..7
3	Turning taps on and off.	1..2..3..4..5..6..7
4	Going to the market.	1..2..3..4..5..6..7
5	Bathing and drying yourself.	1..2..3..4..5..6..7
6	Walking 3 kilometres.	1..2..3..4..5..6..7

Please use this scale to answer the next series of questions: 1=not at all, 2=hardly troubled, 3=somewhat troubled, 4=moderately troubled, 5=quite troubled, 6=very troubled, 7=extremely troubled.

How troubled have you been in the last week by each of these social or occupational activities as a result of your SLE?

7	Work and school performance.	1..2..3..4..5..6..7
8	Interference with my career or education.	1..2..3..4..5..6..7
9	Missing work or school.	1..2..3..4..5..6..7
10	Relationship with friends and relatives.	1..2..3..4..5..6..7
11	Taking part in sports.	1..2..3..4..5..6..7
12	Sex.	1..2..3..4..5..6..7
13	Taking part in social activities.	1..2..3..4..5..6..7
14	Unable to go out under the sun.	1..2..3..4..5..6..7
15	Making less money because I have SLE.	1..2..3..4..5..6..7

How troubled have you been by each of these symptoms in the last week as a result of your SLE?

16	Poor memory	1..2..3..4..5..6..7
17	Loss of appetite	1..2..3..4..5..6..7
18	Fatigue	1..2..3..4..5..6..7

19	Poor concentration	1..2..3..4..5..6..7
20	Itchy skin.	1..2..3..4..5..6..7
21	Sore mouth	1..2..3..4..5..6..7
22	Sore, painful or stinging skin.	1..2..3..4..5..6..7
23	Joint pain and swelling.	1..2..3..4..5..6..7

Please use this scale to answer the next series of questions: 1=not at all, 2=hardly troubled, 3=somewhat troubled, 4=moderately troubled, 5=quite troubled, 6=very troubled, 7=extremely troubled.

How troubled have you been by each of these problems related to medical treatment in the last week as a result of your SLE?

24	Fear of needles.	1..2..3..4..5..6..7
25	Dietary restrictions.	1..2..3..4..5..6..7
26	Inconvenience of daily medication	1..2..3..4..5..6..7
27	Inconvenience of frequent clinic visits	1..2..3..4..5..6..7

Please use this scale to answer the rest of the questions: 1=not at all, 2=hardly ever, 3=somewhat often, 4=moderately often, 5=quite often, 6=very often, 7=extremely often.

How often during the last week have you been troubled by these emotions as a result of your SLE?

28	Self-consciousness.	1..2..3..4..5..6..7
29	Feeling low.	1..2..3..4..5..6..7
30	Depression.	1..2..3..4..5..6..7
31	Anxiety.	1..2..3..4..5..6..7

How often in the last week have you been troubled by these feelings as a result of your SLE?

32	I wish that other people did not know that I have SLE.	1..2..3..4..5..6..7
33	Being made fun of by my friends and colleagues.	1..2..3..4..5..6..7
34	Low self esteem.	1..2..3..4..5..6..7
35	Embarrassment about my SLE.	1..2..3..4..5..6..7
36	Concern about the financial burden to my family.	1..2..3..4..5..6..7
37	Concern that medicines do not work.	1..2..3..4..5..6..7
38	Concern about side effects of medicines.	1..2..3..4..5..6..7
39	Fear of receiving bad news from doctors.	1..2..3..4..5..6..7
40	Consuming more alcohol or tobacco.	1..2..3..4..5..6..7