EUROPEAN REGISTRY OF SEVERE CUTANEOUS ADVERSE REACTIONS TO DRUGS AND COLLECTION OF BIOLOGICAL SAMPLES

RegiSCAR

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5 Year-Questionnaire

Interview no.

SJS/TEN ☐

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EUROPEAN REGISTRY OF SEVERE CUTANEOUS ADVERSE REACTIONS TO DRUGS AND COLLECTION OF BIOLOGICAL SAMPLES

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5 Year-Questionnaire

Interview no.

☐☐☐ ☐☐☐☐

GENERAL DATA

Please fill in the actual date

☐☐☐☐☐☐

Initials of the patient

☐☐

date of birth

☐☐☐☐☐☐

Five years ago you were hospitalized for a severe skin reaction.

Dr.

____
(name)

from the department of dermatology in .... came to visit you. You agreed to participate in a follow-up surveillance. We would be grateful to hear how you feel today. Please send this questionnaire back to us after answering the following questions. We appreciate your help! Please do not hesitate to contact us for questions and help completing this questionnaire (our phone number: ....)!

5 Year-Questionnaire

1) Are you working?

no ☐ yes ☐

If no, because

☐ I cannot work due to my severe skin reaction

☐ I have never worked

☐ other (please specify):

____

If yes, is your present activity reduced or modified due to your severe skin reaction?

no ☐ yes ☐

If yes, please specifiy:

____

____

Have you applied for pension or seriously handicapped person-status due to your severe skin reaction or the sequelae of your severe skin reaction?

☐ no

☐ pension

☐ seriously handicapped person-status

2) More generally, did you resume your daily activities?

no ☐ yes ☐

If yes,

partially ☐

completely ☐

5 Year-Questionnaire

3a) Do you have one or more of the following skin symptoms due to your severe skin reaction?

Skin:

	no	yes
Pruritus	☐	☐
Dryness	☐	☐
Hypopigmentation of the skin	☐	☐
Hyperpigmentation of the skin	☐	☐
Scars	☐	☐
Increased number of moles	☐	☐
Hypohydrosis	☐	☐
Hyperhydrosis	☐	☐

To what extent does your skin problem affect your daily-life? Please circle only one of the following answers:

not at all / slightly / moderately / quite a bit / extremely

3b) Do you have one or more of the following eye symptoms due to your severe skin reaction?

	no	yes	unknown
Pain	☐	☐	
Sensitivity to light	☐	☐	
Dryness	☐	☐	
Excessive tearing	☐	☐	
Loss of lashes	☐	☐	
Inside growth of lashes	☐	☐	
Visual impairment related to your severe cutaneous adverse reaction	☐	☐	☐

Do you use due to your eye problems:

	no	yes
Drops	☐	☐
Lenses	☐	☐
Glasses	☐	☐
Sunglasses	☐	☐
Plastic surgery for eyelids	☐	☐
Eye-specific surgery / transplantates	☐	☐

Due to your eye problems, do you have difficulties in your daily-life activities like reading, working, driving?

no ☐ yes ☐

To what extent does your eye problem affect your daily-life? Please circle only one of the following answers:

not at all / slightly / moderately / quite a bit / extremely

3c) Do you have one or more of the following symptoms due to your severe skin reaction?

Mouth:

	no	yes
Dryness	☐	☐
Pain	☐	☐
Impaired taste	☐	☐
Difficulties in swallowing	☐	☐

To what extent does your mouth problem affect your daily-life? Please circle only one of the following answers:

not at all / slightly / moderately / quite a bit / extremely

Teeth / Gums:

	no	yes
Caries	☐	☐
Problems with teeth	☐	☐
Sore gums	☐	☐
Gingival shrinking	☐	☐
Bleeding sensitivity	☐	☐

To what extent does your teeth/gums problem affect your daily-life? Please circle only one of the following answers:

not at all / slightly / moderately / quite a bit / extremely

5 Year-Questionnaire

Do you have one or more of the following symptoms due to your severe skin reaction?

3d) Lung:

	no	yes
Cough	☐	☐
Dyspnea / shortness of breath	☐	☐
Sputum	☐	☐
Wheezing / rhonchus	☐	☐

To what extent does your lung problem affect your daily-life? Please circle only one of the following answers:

not at all / slightly / moderately / quite a bit / extremely

3e) Nose:

	no	yes
Bleeding	☐	☐
Dryness	☐	☐
Chronic irritation	☐	☐
Pain	☐	☐
Running nose	☐	☐

To what extent does your nose problem affect your daily-life? Please circle only one of the following answers:

not at all / slightly / moderately / quite a bit / extremely

5 Year-Questionnaire

Do you have one or more of the following symptoms due to your severe skin reaction?

3f) Genital mucosa:

	no	yes
Dryness	☐	☐
Pain	☐	☐
Adhesions	☐	☐
Difficulties in urinating	☐	☐
Impaired sexuality	☐	☐

To what extent does your genital problem affect your daily-life? Please circle only one of the following answers:

not at all / slightly / moderately / quite a bit / extremely

3g) Nails:

	no	yes
Loss of fingernails	☐	☐
Loss of toenails	☐	☐
Other nail abnormalities	☐	☐

If yes, type of abnormalities: ____

To what extent does your nail problem affect your daily-life? Please circle only one of the following answers:

not at all / slightly / moderately / quite a bit / extremely

3h) Hair:

	no	yes
Loss of hair	☐	☐
Other hair abnormalities	☐	☐

If yes, type of abnormalities: ____

To what extent does your hair problem affect your daily-life? Please circle only one of the following answers:

not at all / slightly / moderately / quite a bit / extremely

3i) Have you observed a higher sensibility to the following infections?

	no	yes
Sinusitis	☐	☐
Bronchitis	☐	☐
Influenza	☐	☐
Cystitis	☐	☐
Renal pelvis inflammation	☐	☐
Vaginitis	☐	☐
Stomatitis	☐	☐
Conjunctivitis	☐	☐
Other infections	☐	☐

If yes, please specifiy:

____

____

5 Year-Questionnaire

3j) Have you been diagnosed to one of the following diseases since your severe skin reaction?

	no	yes
Lupus erythematosus	☐	☐
Thyroiditis	☐	☐
Rheumatoid arthritis	☐	☐
Crohn's disease	☐	☐
Multiple sclerosis	☐	☐
Other diseases	☐	☐

If yes, please specifiy:

____

____

Do you suffer from any other sequelae due to your severe skin reaction?

no ☐ yes ☐

If yes, please specifiy:

____

____

Have you been treated for one or several of these sequelae?

no ☐ yes ☐

If yes, please specifiy:

____

____

Do you agree that we obtain information from your treating physician?

no ☐ yes ☐

If yes, please provide the name and address of the treating physician:

____

____

5 Year-Questionnaire

4) Did you experience any of the following in relation to your severe skin reaction? (Several answers are possible)

- Aesthetic embarassement

no ☐ yes ☐

If yes, to what extent does it affect your daily-life? Please circle only one of the following answers:

not at all / slightly / moderately / quite a bit / extremely

- Impaired sleeping

no ☐ yes ☐

If yes, to what extent does it affect your daily-life? Please circle only one of the following answers:

not at all / slightly / moderately / quite a bit / extremely

- Bad dreams

no ☐ yes ☐

If yes, to what extent does it affect your daily-life? Please circle only one of the following answers:

not at all / slightly / moderately / quite a bit / extremely

- Are you afraid of medications?

no ☐ yes ☐

If yes, to what extent does it affect your daily-life? Please circle only one of the following answers:

not at all / slightly / moderately / quite a bit / extremely

5 Year-Questionnaire

5) Some more questions:

Were you hospitalized again as a consequence of your severe skin reaction?

no ☐ yes ☐

If yes, total number of days: ☐☐☐

Did you avoid using drugs after your severe skin reaction?

no ☐ yes ☐

If yes, please circle one or more of the following:

oral medication / topical medication / vaccination / i.v.-medication / dental injections /
(i.e., creams)

other: ____

Did you avoid medical or dental care after your severe skin reaction?

no ☐ yes ☐

Did you get professional psychological support because of your severe skin reaction?

no ☐ yes ☐

If yes, please specify:

____

Do you think professional psychological support would be helpful?

no ☐ yes ☐

5 Year-Questionnaire

Have you experienced additional adverse reactions due to medication use after your severe skin reaction?

no ☐ yes ☐

If yes, did it affect the skin?

no ☐ yes ☐

If no, what was affected?

____

Additonal remarks that you would like to make:

____

____

____

Thank you for answering our questions!

Please never hesitate to contact us whenever we can provide our help!

All the best for you!