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

RegiSCAR

---

1 Year-Questionnaire

Interview no.

SJS/TEN ☐

This is a confidential document of high importance for health research. In case of loss, if someone finds it, please send it to the following address:

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

RegiSCAR
1 Year-Questionnaire

Interview no.
☐☐☐ ☐☐☐☐

GENERAL DATA

Please fill in the date
of 1 year-follow-up
☐☐☐☐☐☐

Initials of the patient
☐☐

date of birth
☐☐☐☐☐☐

One year ago when hospitalized for a severe cutaneous adverse reaction (SCAR) also doctor

____
(name)

from our dermatological department came to visit you. You agreed to participate in a follow-up surveillance. Thank you for 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: ....)!

1 Year-Questionnaire

1) Were you working before the severe cutaneous adverse reaction (SCAR), including school?

no yes

If yes, did you resume your work (or school)?

no yes

If yes, when? date

partially

completely

If no, why not?

---

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

no yes

If yes, partially date

completely date

1 Year-Questionnaire

3) Have you been suffering from the following symptoms due to your severe cutaneous adverse reaction (SCAR)?

Skin:

	no	yes		no	yes
Pruritus	☐	☐	**If yes,** still present:	☐	☐
Dryness	☐	☐	**If yes,** still present:	☐	☐
Hypocoloration of the skin	☐	☐	**If yes,** still present:	☐	☐
Hypercoloration of the skin	☐	☐	**If yes,** still present:	☐	☐
Scars	☐	☐	**If yes,** still present:	☐	☐

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

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

Interview no. ☐☐☐ ☐☐☐☐

1 Year-Questionnaire

Eyes:

	no	yes		no	yes
Pain	☐	☐	**If yes,** still present:	☐	☐
Sensitivity to light	☐	☐	**If yes,** still present:	☐	☐
Dryness	☐	☐	**If yes,** still present:	☐	☐
Excessive tearing	☐	☐	**If yes,** still present:	☐	☐
Loss of lashes	☐	☐	**If yes,** regrown:	☐	☐
Inside growth of lashes	☐	☐	**If yes,** still present:	☐	☐

Visual impairment related to SCAR no ☐ yes ☐ unknown ☐

If yes, visual acuity ☐☐ left eye visual acuity ☐☐ right eye

Are you followed by an ophthalmologist?

no ☐ yes ☐ **If yes,** when was the last examination? date ☐☐☐☐☐☐

Do you agree that we obtain information from your ophthalmologist?

no ☐ yes ☐ **If yes,** please provide name and address (capital letter):

____

____

What is the diagnosis of your ophthalmologist?

____

Interview no. ☐☐☐ ☐☐☐☐

1 Year-Questionnaire

Due to your eye-problems, do you have problems in your daily-life activities like:

	no	yes
Reading, working, driving?	☐	☐

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

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

Mouth:

	no	yes		no	yes
Dryness	☐	☐	**If yes,** still present:	☐	☐
Pain	☐	☐	**If yes,** still present:	☐	☐
Impaired taste	☐	☐	**If yes,** still present:	☐	☐

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

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

Genitalia:

	no	yes		no	yes
Dryness	☐	☐	**If yes,** still present:	☐	☐
Pain	☐	☐	**If yes,** still present:	☐	☐
Genital adhesions	☐	☐	**If yes,** still present:	☐	☐
Impaired sexuality	☐	☐	**If yes,** still present:	☐	☐

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

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

1 Year-Questionnaire

Nails:

	no	yes		no	yes
Loss of fingernails	☐	☐	**If yes,** regrown:	☐	☐
Loss of toe nails	☐	☐	**If yes,** regrown:	☐	☐
Abnormalities	☐	☐			

If yes, type of abnormalities: ______________________________

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

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

Hair:

	no	yes		no	yes
Loss of hair	☐	☐	**If yes,** regrown:	☐	☐
Abnormalities	☐	☐			

If yes, type of abnormalities: ______________________________

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

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

Do you suffer from any other sequelae?

no ☐ yes ☐

If yes, please specify:

____

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

no ☐ yes ☐

If yes, please specify:

____

____

1 Year-Questionnaire

4) Did you notice the appearance or worsening of any of the following after your severe cutaneous adverse reaction (SCAR)?

- Aesthetic embarassement no ☐ yes ☐

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

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 one of the following:

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 one of the following:

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 one of the following:

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

1 Year-Questionnaire

5) Some more questions:

Were you hospitalized again as a consequence of your severe cutaneous adverse reaction (SCAR)?

no ☐ yes ☐

If yes, total number of days: ☐☐☐

After your severe cutaneous adverse reaction (SCAR) did you avoid using drugs?

no ☐ yes ☐

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

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

other: ____

After your severe cutaneous adverse reaction (SCAR) did you avoid medical or dental care?

no ☐ yes ☐

Did you get professional psychological support because of your severe cutaneous adverse reaction (SCAR)?

no ☐ yes ☐

If yes, please specify:

____

Do you think professional psychological support would be helpful?

no ☐ yes ☐

1 Year-Questionnaire

Do you consider that your questions about your disease have been adequately answered?

not at all ☐ only partially ☐ mostly ☐ completely ☐

Has the cause of your disease been detected?

no ☐ yes ☐

If yes, please name it as specific as possible:

____

Have you received written advice to avoid specific medication?

no ☐ yes ☐

If yes, which one?

____

Thank you for answering our questions!

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

All the best for you!