

Supplemental material 1: Online survey for DEGUM specialists

Question 1: Where do you work?

- Outpatient clinic
- Hospital

Question 2: Which DEGUM level do you have?

- DEGUM-Stufe I
- DEGUM-Stufe II
- DEGUM-Stufe III
- None

Question 3: How many pregnant women with anti-Ro/La antibodies do you see each year?

- None
- 1-5
- 6-10
- Over 10

Question 4: Does the laboratory you work with perform purely qualitative or also (semi-) quantitative measurements of antibodies (anti-Ro/anti-La)?

- Yes
- No
- I don't know

Question 5 - Which drug prophylaxis do you consider appropriate for a primigravida with anti-Ro/anti-La antibodies?

- Fluorinated glucocorticoids (dexamethasone/betamethasone)
- Hydroxychloroquine
- Immunoglobulins (IVIg)
- Other: _____
- None

Question 6 - What prophylactic medication do you consider useful for pregnant women with an affected previous pregnancy?

- Fluorinated glucocorticoids (dexamethasone/betamethasone)
- Hydroxychloroquine
- Immunoglobulins (IVIg)
- Other: _____
- None

Question 7 - How often do you perform echocardiography on anti-Ro/La positive pregnant women between the (16th) 18th and 26th week of pregnancy?

- Weekly
- Every 2 weeks
- Different scheme

- I do not perform intensified monitoring
- I do not consider intensified monitoring by means of echocardiography to be useful

Question 8 - Do you instruct pregnant women on home monitoring (self-monitoring by a hand-held doppler device)?

- Yes
- No

Question 9 - Is this something you could imagine doing in the future?

- Yes
- No

→ If not, why not?

Question 11 - How do you treat an AV block I°?

- Not at all
- Fluorinated glucocorticoids (dexamethasone/betamethasone)
- Immunoglobulins (IVIg)
- Fluorinated glucocorticoids (dexamethasone/betamethasone) + IVIg
- Hydroxychloroquine
- Betamimetics

Question 12 - How do you treat an AV block II°?

- Not at all
- Fluorinated glucocorticoids (dexamethasone/betamethasone)
- Immunoglobulins (IVIg)
- Fluorinated glucocorticoids (dexamethasone/betamethasone) + IVIg
- Hydroxychloroquine
- Betamimetics

Question 13 - How do you treat a complete AV block?

- Not at all
- Fluorinated glucocorticoids (dexamethasone/betamethasone)
- Immunoglobulins (IVIg)
- Fluorinated glucocorticoids (dexamethasone/betamethasone) + IVIg
- Betamimetics

Question 14 - In your opinion, how quickly can a complete AV block develop?

- Under 12h
- 12-24h
- Over 24h
- I don't know

Question 15 - Do you think that the course of the disease and the associated prognosis of the fetus can be improved by prompt diagnosis and treatment?

- Yes

- No
- I don't know

Question 16 - Do you think the current practice of weekly fetal echocardiography with monitoring of PR conduction makes sense?

- Yes
- No
- I don't know

→ If not, why not?

Question 17 – Are you able to start a treatment with immunoglobulins within 12 hours in the setting in which you work/the infrastructure in which you work?

- Yes
- No

Question 18 – Would you like to have a cut- off value for anti-Ro/anti-La antibodies for specific risk classification and risk-adapted monitoring?

- Yes
- No
- I don't know

Question 19 - Suggestions and proposals.

Supplement material 2: questionnaire for study participants

1. Age: _____

2. Height: _____

3. Weight: _____

4. Gestational age at initial visit: _____

5. Gestational age at the beginning of the study: _____

6. Distance to the center: up to 50km 50-100km over 100km

7. Ethnicity: PoC Hispanic Caucasian Asian

Mixed Other: _____

8. Highest level of education: Secondary school High school
 University degree

9. Language skills

Language	No skills	Bad skills	Moderate skills	Good skills	Fluent
German	<input type="radio"/>				
English	<input type="radio"/>				
Turkish	<input type="radio"/>				
Arabic	<input type="radio"/>				
Other:	<input type="radio"/>				
Other:	<input type="radio"/>				

10. Medications: _____

Was your medication changed due to the pregnancy? Yes No

If so, what has been changed:

11. Have you been diagnosed with a rheumatic disease? Yes No

If so, which:

- a) Lupus erythematosus
- b) Sjögren syndrome
- c) Antiphospholipid syndrome
- d) Rheumatoid arthritis
- e) Other : _____

12. How long ago has your rheumatic disease been diagnosed? Since _____

13. Who has made the diagnosis? _____

14. Any previous pregnancies? Yes No

If yes:

Type of delivery: Natural birth C-section

Weight of the newborn: _____

Gestational age at delivery: _____

Do you have a child affected by neonatal lupus? Yes No

Complications during pregnancy? Yes

No

If yes:

Pre-eclampsia Growth retardation Hypertension

Other: _____

15. Have you ever had a miscarriage before?? Yes No

If yes, at what gestational age? _____

16. How many times have you been pregnant (before the current pregnancy)?

0 1 2 3 4 5 more than 5

17. How many births have you had?

0 1 2 3 4 5 more than 5

18. Have you and your partner ever had an ICSI (intracytoplasmic sperm injection)?

Yes. No

19. Have you planned the current pregnancy?

Yes No

20. Did your gynecologist/rheumatologist have a consultation with you before your pregnancy?

Yes No

21. Do you think that your gynecologist has provided you with sufficient information about special aspects of the course of your pregnancy or monitoring?

Yes No

22. Do you think that your rheumatologist has provided you with sufficient information about special aspects of the pregnancy process or monitoring?

Yes No

23. Do you feel restricted in your everyday life by your illness?

Yes No

24. Do you feel that your illness is a burden?

Yes No

25. Do you worry a lot during this pregnancy?

Yes, I am worried a lot. <input type="radio"/>	Yes, I am worried. <input type="radio"/>	I am partly concerned, partly not. <input type="radio"/>	No, I am not worried. <input type="radio"/>	No, I am not worried at all. <input type="radio"/>
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Weekly documentation form

1. Please enter the date and the measured heart rates in the following table.

	Date:						
Heart rate							
Morning							
Noon							
Evening							

2. How often were you not able to measure?

This week it was not possible for me to measure _____ times.

3. This week I have felt _____ by the measurement. (Please check the box)

	Totally agree	Agree	Neither agree nor disagree	Disagree	Don't agree at all
Stressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strengthened	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. Have you contacted the center?

	Yes	No
Contact	<input type="radio"/>	<input type="radio"/>
If so, how often?		

Evaluation of the documentation form

Non-subjective parameters:

1. Number of contacts made: _____

Why: Slow heart rate Irregular heart rate Heart rate not derivable

Other: _____

2. Correct contacts: _____

3. False alarm: Yes No

4. If so, what reasons?

5. Were there any pregnant women who discontinued self-monitoring?

Yes No

If so, why? _____