

## **Questionnaire on pregnancy with inherited heart disease (ARVC-Selbsthilfe e.V. Germany)**

### **A. Questions on medical aspects**

1. Are you (a) an ARVC patient with symptoms, or (b) a mutation carrier without symptoms?
2. Was your condition/mutation diagnosed before, during or after pregnancy?
3. Did cardiac arrhythmia or palpitations (or your perception of it) increase or improve during pregnancy, or did it occur for the first time?
4. Were the subjective perceptions confirmed by examinations (deterioration of findings, e.g. in Holter monitoring, echo or MRI)?
5. Were the findings temporary (only during the whole / part of the pregnancy) or permanent? At what point in the pregnancy did a (subjective or objective) deterioration occur and in case it was temporary when did it stop?
6. Was there any change in your medication during pregnancy and/or breastfeeding? Please give details.
7. Was there anything unusual during pregnancy, delivery or in the weeks following delivery that you wish to mention?

### **B. Questions on psychological/mental aspects**

8. What were the biggest challenges for you in terms of pregnancy against the background of your mutation or your condition?
9. What helped you feel well during pregnancy physically and mentally (as much as possible)? What would you do differently in retrospect?
10. What would you have liked to know beforehand (e.g. support options, medical aspects...)?
11. What would you like to tell women with the condition who are pregnant or are thinking of becoming pregnant?
12. What other experiences would you like to share?

### **C. Questions on pre-pregnancy**

13. Did you seek advice before your pregnancy on family planning issues? If so, by whom (e.g. cardiologist, gynecologist, geneticist, pediatrician)? Did the counselling influence your decision?
14. Did you consider the option of pre-implantation diagnostics (PID, testing of the embryo for your mutation) before your pregnancy? Did you decide for or against this option? What were your reasons?

### **D. General questions about your pregnancy**

15. At what age did you become pregnant?
16. Were there other risks during pregnancy?
17. What was the outcome of the pregnancy?  
E.g. delivery in the xx. week of pregnancy (spontaneous, Caesarean section, vacuum extraction, forceps delivery), miscarriage, ...

### **E. Additional questions**

18. How many cardiological check-ups did you have during your pregnancy?
19. Did your condition (ARVC) or mutation carrier status influence your choice of where to deliver your baby? If so, how?
20. Was there any cooperation between gynecologists and cardiologists and were you satisfied with it? What could be improved?
21. What needs were met or not met around pregnancy? What was missing?