

A tool to help you make an informed decision about PMS Research Study Participation

With growing numbers of PMS clinical research studies, there may be more than one research study in which a person with PMS may be eligible to participate. This is a tool to help you determine which research study or studies in which to participate.

| What's the name of the research study? | | | | | | |
|--|---|--------------------|--------------------|--|---|----|
| Questions to ask the study doctor or coordinator | Rate the importance of the question in making your decision about whether or not to participate in the study. | | | What did the study doctor or coordinator tell you? | Can you accept the degree of burden/visits/benefits, risk, etc. based on the information you were given to each question? | |
| | Very important | Somewhat important | Not very important | | Yes | No |
| 1. What is the purpose of the research study? | | | | | | |
| 2. How long does my child have to participate in the study? | | | | | | |
| 3. How often does my child have to come to the clinic/hospital for the study? | | | | | | |
| 4. Approximately how many hours does my child have to spend at each visit? | | | | | | |
| 5. What kinds of tests or procedures will be done? | | | | | | |
| 6. What are the benefits of participating in this study? | | | | | | |
| 7. What are the risks of participating in this study? | | | | | | |
| 8. Are there any costs that I will have to pay, such as parking or meals during the study visit? | | | | | | |
| 9. Is there any compensation for participating in this study? | | | | | | |
| 10. Will the results of the research study be shared with study participants after the study is completed? | | | | | | |