



Research Study/Protocol Policy: Solicitation of PRISMS families to participate in research studies via the website, PRISMS Facebook page, and/or newsletter, *Spectrum*.

The PRISMS Professional Advisory Board has developed a policy regarding posting research studies/opportunities on the PRISMS URL (www.prisms.org). The policy requires completion of the following form and submission of documents for review and approval by at least two PAB members and one PRISMS Board member and/or parent representative. This is to ensure that the study has been reviewed by an institutional review board (IRB) so as to ensure protection of human subjects and offers a strong likelihood of expanding knowledge about SMS to the benefit of persons and families impacted by the syndrome. In most cases the review is a quick process.

Upon approval of this research study, PRISMS will require the requestor to submit an article for *Spectrum*, The PRISMS Journal for Smith-Magenis Syndrome. The article should detail the goals and outcome of the research project and is expected within a reasonable timeframe. This information will be shared with the PRISMS community.

Please provide the following:

1. Study title:	
2. Principal investigator (name/affiliation):	
3. Co-investigator(s) (name/affiliation):	
4. Abstract/project goals:	
5. Attach copy of IRB approved consent document:**	
6. Attach copy of survey or questionnaire:	
7. Attach recruitment letter or text of web posting:	
8. Attach copy of IRB approval letter:**	

9. Timeline for posting:	Begin: End:
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**IRB approval *is required* for all studies for final PRISMS approval. If IRB approval is pending or requires PRISMS pre-approval before review, please explain above.

Please return this form with attachments by email to:

Emily Fields
Executive Director
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efields@prisms.org