

Request to Use International SMA Patient Registry

Thank you for your interest in utilizing the resources offered by the International SMA Patient Registry. Please complete the following:

PI Name:

Institution:

Address:

City: State: Zip:

Phone #: Fax #:

Email:

Study Coordinator Name:

Phone #: Fax #:

Email:

PROJECT TITLE:

You will need to submit the following documents with your request:

- Study proposal, should outline study design, study purpose, method of data collection with complete example provided (e.g. proposed questionnaire, phone screen, etc.)
- Informed consent
- IRB approval from institution
- Inclusion/exclusion criteria
- Number of participants needed for this study

Your request and supporting documents will be reviewed by the International SMA Patient Registry Oversight Committee. Upon approval, we will contact you about preparing a subject recruitment letter that will go to registry participants. Please remember that:

- There is no cost for using the International SMA Patient Registry.
- The International SMA Patient Registry must be cited in any publications, conferences, or any other presentations of material resulting from the International SMA Patient Registry use. Use the acknowledgement language below:
 - *“This study acknowledges the collaboration of the International Spinal Muscular Atrophy Patient Registry (Indiana University) which is supported by the Patient Advisory Group of the International Coordinating Committee for SMA Clinical Trials which includes Families of SMA, Fight SMA, Muscular Dystrophy Association, SMA Foundation, and other SMA advocacy groups.”*
- The International SMA Patient Registry should receive a copy of any cited materials for our files.