

Application for use of data/samples from ARISEN

1. Date of Application:
2. Title of project:
3. Principal investigator (Name, title, and affiliation):
4. Co-investigator(s) including name(s), title(s) and affiliation(s):
5. Primary contact name and email:
6. Complete contact address:
7. Estimated start and end dates of the project:
8. Funding source (include those sources already obtained and plans for future grant submission with dates, if applicable):
9. Please attach a project summary including background/rationale, hypothesis, aims, methods, preliminary data, intended use of data/samples, and brief statistical analysis plan including who will perform this analysis. *Please keep this to one page, single spaced, 1 inch margins, size 11 font, including figures and tables, not including references.*
10. Please include an excel file with the data points highlighted that are needed for the project.
11. Please detail type of biospecimens requested, including justification for number, type and quantity of specimen requested

Type of Sample	Participant (AE, RE, NORSE)	Number of Samples	Volume/Concentration per sample

12. Please acknowledge that you agree with the following conditions:
 - a. All results from research projects involving samples from the ARISEN biorepository need to be provided back to us for inclusion in the ARISEN research database (in a de-identified manner), which is open to qualifying researchers. These results must be provided within one year of completion of the project, using the end date you provided above. You may also request a one-year extension for this deadline if needed.
 - b. All applications **must include the appropriate NIH grant number** supporting the Rare Diseases Clinical Research Network (RDCRN) consortium and must use the following acknowledgment in all publications, presentations, press releases, and research products resulting from this project:

“This project is supported by the Rare Diseases Clinical Research Network (RDCRN), an initiative of the National Center for Advancing Translational Sciences (NCATS) and the Eunice Kennedy Shriver National Institute Of Child Health & Human Development, funded through the National Institutes of Health (NIH) Grant Number: U54HD122209. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.”

- c. Prior to submitting any related publications, including manuscripts, abstracts, and/or presentations please let us know so we can ensure that all relevant co-authors are included.
- d. You will share data and samples from your prior, current and future ARISEN patients when feasible and appropriate based on consent and on your participation in the ongoing multicenter study.

Please confirm that you understand and will comply with these conditions by signing below.

Printed Name

Signature