Frequently Asked Questions:
About FA-ICD data:

Q: What data does FA-ICD presently host?

A: FA-ICD currently contains placebo arm data from four clinical trials (Santhera's Ionia and Miconos trials, Apopharma's deferiprone trial, and Bioelectron's trial of EPI-743) and the FARA-sponsored FA Clinical Outcome Measure Study. (FA-COMS).

Q: How are the data standardized?

A: Data are mapped to the Clinical Data Interchange Standards Consortium (CDISC) Standard Data Tabulation Model (SDTM) to maximize utility of aggregated data for statistical analysis. All data are fully anonymized.

Q. Who owns the data?

A: The organizations that own these data, referred to as Sponsors, have agreed to provide them to FA-ICD with defined provisions that are addressed in individual Data Contribution Agreements; Sponsors maintain ownership of any data contributed. Critical Path Institute does not "own" these data.

Q: Does the database include treatment arm data?

A: If Sponsors are willing to share treatment arm data, it will be included in the database. However, at the current time only placebo arm and natural history data are in the database.

Q: Will more data be added to FA-ICD over time?

A: As it becomes available, new datasets will be added. Existing users will be notified when new data is added to the platform.

Q: If the database efforts are concluded, what happens to the data housed by C-Path?

A: C-Path and FARA have use of the data based on agreements with the Sponsors. FA-ICD does not "own" the data. When database efforts are concluded, data will be handled in the manner as agreed upon with the Sponsor.

Access to FA-ICD data:

Q: Is FA-ICD available to the scientific community?

A: Yes. Researchers doing work in FA may request access to the database, which includes providing a reasonable explanation of the intended use of the data, and agree to defined terms and conditions for privacy protection, data security, acknowledgement of the source of the data, and preview of any scientific publications resulting from use of the data. All data access requests will be reviewed by a steering committee consisting of representatives of C-Path, FARA and the FA community.

Q: How do I apply for access to FA-ICD?
A: Visit the FA-ICD page on this website to apply for access. You must first review and agree to the Terms and Conditions for Use. Once completed, you will be directed to the online application form.

Q: How long will it take to process my access request?
A: The FA-ICD steering committee will review all user access applications in a timely manner; this may take up to 4 weeks.

Q: What form will the data be available in?

A: Data may be downloaded from the FA-ICD platform as a SAS file or as a comma separated values (CSV) file.

Q: Is there a cost for using FA-ICD?

A: There is no cost to access this data.

Comments on the FA-ICD database:

Q: How do I suggest improvements to the FA-ICD?
A: We appreciate suggestions on improvements to the FA-ICD. Please send your comments and suggestions to Richard Liwski (rliwski@c-path.org).