Frequently Asked Questions
About FA-ICD data:

Q: What data does FA-ICD presently host?
A: FA-ICD currently contains placebo arm data from six clinical trials and the FARA- sponsored, natural history study, 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, screening/baseline from treatment arms, and natural history data are in the database for external users.

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 database.

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.

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 agreeing to: (1) defined terms and conditions for privacy protection and data security, (2) including an acknowledgement of the source of the data in any scientific communication, and (3) providing a 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: For access via CODR, please visit the FA-ICD page on this website to apply. You must first review and agree to the Terms and Conditions for Use. Once completed, you will be directed to the online application form.
For access via RDCA-DAP, please visit https://c-path.org/programs/rdca-dap/ for more information or contact rdcadap@c-path.org.

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.

Q: How do I contribute data?
A: FA-ICD encourages data contributions from interventional and non-interventional studies. Please contact Alexandre Betourne, abetourne@c-path.org or rdcadap@c-path.org for inquiries and to be guided through the process. In general, for contribution to RDCA-DAP, custodians of the data need to sign a Data Contribution Agreement with C-Path and de-identify the data to ensure all consent and data privacy regulations are met and to designate how RDCA-DAP may use and share the data. Once this is completed, the data may be transferred from the contributor into RDCA-DAP.

Q: What is the Rare Disease Cures Accelerator – Data and Analytics Platform (RDCA-DAP)?
A: The Rare Disease Cures Accelerator-Data and Analytics Platform (RDCA-DAP) is a database containing information about a range of rare diseases, coupled with an analytical framework to help understand that data. In addition to CODR, RDCA-DAP also hosts the FA-ICD. For more information, please visit https://c-path.org/programs/rdca-dap/.

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 email your comments and suggestions to Alexandre Betourne (abetourne@c-path.org) and Richard Liwski (rliwski@c-path.org).