

The Pediatric Acute Liver Failure (PALF) Cohort Study Data Archive

Acute liver failure (ALF) is a condition in which liver function rapidly deteriorates. ALF often affects young people and causes serious, and sometimes fatal, complications. Treatment of the disease is dependent upon its cause, which can be numerous factors. Because recovery from this disease is random, there is no way to predict how a patient will respond to treatment. Sometimes a liver transplant is required in order for a patient to make a full recovery. The mission of the Pediatric Acute Liver Failure (PALF) study is to develop methods to predict whether a child will require a life-saving procedure in order to recover from the illness.

The PALF data archive contains data collected for PALF Phases 1, 2, and 3.

Archive files are organized into the following directories:

- Data
- Documents
- Dataset Integrity Check (DSIC)
- Forms

Data

The PALF Data directory contains the following files and datasets in Windows-based SAS and CSV formats, with corresponding codebooks and SAS formats:

- formats.sas

Data\Phase 1 and 2\NAC

- NC.CSV
- nc.sas7bdat
- NF.CSV
- nf.sas7bdat
- RAND.CSV
- rand.sas7bdat
- SAE.CSV
- sae.sas7bdat

Data\Phase 1 and 2\NAC\Codebooks

- NC_NAC Trial Criteria_codebook.pdf
- NF_NAC Form_codebook.pdf

Data\Phase 1 and 2\NAC\Proc_Contents

- PALF_NC_proc contents.rtf
- PALF_NF_proc contents.rtf
- PALF_RAND_proc contents.rtf
- PALF_SAE_proc contents.rtf

Data\Phase 1 and 2\Registry

- EL.CSV
- el.sas7bdat
- FF.CSV

- ff.sas7bdat
- FV.CSV
- fv.sas7bdat
- HE.CSV
- he.sas7bdat
- HF.CSV
- hf.sas7bdat
- RC.CSV
- rc.sas7bdat
- SC.CSV
- sc.sas7bdat

Data\Phase 1 and 2\Registry\Codebooks

- EL_Enrollment Log_codebook.pdf
- FF_Follow-up Form_codebook.pdf
- FV_Follow-up Vital Status_codebook.pdf
- HE_Hospitalization Evaluation_codebook.pdf
- HF_Hospitalization Flowsheet_codebook.pdf
- RC_Registry Criteria_codebook.pdf
- SC_Sample Collection Checklist_codebook.pdf

Data\Phase 1 and 2\Registry\Proc_Contents

- PALF_EL_proc contents.rtf
- PALF_FF_proc contents.rtf
- PALF_FV_proc contents.rtf
- PALF_HE_proc contents.rtf
- PALF_HF_proc contents.rtf
- PALF_RC_proc contents.rtf
- PALF_SC_proc contents.rtf

Data\Phase 1 and 2\Supplemental Tests

- Supplemental Tests Read Me File.pdf

Data\Phase 1 and 2\Supplemental Tests\APAP

- apap.sas7bdat
- APAP.CSV
- APAP_proc contents.rtf

Data\Phase 1 and 2\Supplemental Tests\Date_of_Evaluation

- doedate_update.sas7bdat
- DOEDATE_UPDATE.CSV
- DOEDATE_update_proc contents.rtf

Data\Phase 1 and 2\Supplemental Tests\Diagnostic Labs

- PALF_SUPP_TESTS_DAILY_proc contents.rtf

- PALF_SUPP_TESTS_proc contents.rtf
- supp_tests.sas7bdat
- SUPP_TESTS.CSV
- supp_tests_daily.sas7bdat
- SUPP_TESTS_DAILY.CSV

Data\Phase 1 and 2\Supplemental Tests\Inflammatory Biomarkers

- PALF_YORAM_SUP_proc contents.rtf
- YORAM_SUP.CSV
- yoram_sup.sas7bdat

Data\Phase 1 and 2\Supplemental Tests\NK_Cell

- NKCELL.CSV
- nkcell.sas7bdat
- nkcell_proc contents.rtf

Data\Phase 1 and 2\Supplemental Tests\Supplemental information and final diagnoses

- SI_DIAG PROC CONTENTS.rtf
- SI_DIAG.CSV
- si_diag.sas7bdat

Data\Phase 3

- AI.CSV
- ai.sas7bdat
- BG.CSV
- bg.sas7bdat
- CD.CSV
- cd.sas7bdat
- CP.CSV
- cp.sas7bdat
- DG.CSV
- dg.sas7bdat
- EV.CSV
- ev.sas7bdat
- FP.CSV
- fp.sas7bdat
- GA.CSV
- ga.sas7bdat
- GC.CSV
- gc.sas7bdat
- IF.CSV
- if.sas7bdat
- IN.CSV
- in.sas7bdat
- LO.CSV

- lo.sas7bdat
- MD.CSV
- md.sas7bdat
- MT.CSV
- mt.sas7bdat
- NE.CSV
- ne.sas7bdat
- OP.CSV
- op.sas7bdat
- PA.CSV
- pa.sas7bdat
- PF.CSV
- pf.sas7bdat
- PI.CSV
- pi.sas7bdat
- PL.CSV
- pl.sas7bdat
- PQIA.CSV
- pqia.sas7bdat
- PQIB.CSV
- pqib.sas7bdat
- PQPF.CSV
- pqp.f.sas7bdat
- PQPGB.CSV
- pqp.gb.sas7bdat
- PQPGC.CSV
- pqp.gc.sas7bdat
- PQPGT.CSV
- pqp.gt.sas7bdat
- PQPGY.CSV
- pqp.gy.sas7bdat
- PQSFC.CSV
- pqsfc.sas7bdat
- PQSFT.CSV
- pqsft.sas7bdat
- PQSFY.CSV
- pqsfy.sas7bdat
- PQSGC.CSV
- pqsgc.sas7bdat
- PQSGT.CSV
- pqsgt.sas7bdat
- PQSGY.CSV
- pqsgy.sas7bdat
- PR.CSV

- pr.sas7bdat
- SE.CSV
- se.sas7bdat
- SF.CSV
- sf.sas7bdat
- SM.CSV
- sm.sas7bdat
- SP.CSV
- sp.sas7bdat
- TB.CSV
- tb.sas7bdat
- UN.CSV
- un.sas7bdat
- VI.CSV
- vi.sas7bdat
- VR.CSV
- vr.sas7bdat

Data\Phase 3\Codebooks

- AI_Autoimmune_codebook.pdf
- BG_Biochemistries - Blood Gases_codebook.pdf
- CD_Biochemistries - CBC with Differential_codebook.pdf
- CP_Biochemistries - Comprehensive Panel_codebook.pdf
- DG_Diagnosis Log_codebook.pdf
- EV_Event Log_codebook.pdf
- FP_Follow-up Form_codebook.pdf
- GA_Global Assessment_codebook.pdf
- GC_Genetics Consent_codebook.pdf
- IF_Infections_codebook.pdf
- IN_Intervention Log_codebook.pdf
- LO_Liver Offer Log_codebook.pdf
- MD_Medication Log_codebook.pdf
- MT_Metabolics_codebook.pdf
- NE_Neurocognitive Criteria_codebook.pdf
- OP_Off_Protocol_codebook.pdf
- PA_Physical Assessment_codebook.pdf
- PF_Patient Information Form_codebook.pdf
- PI_Patient Initialization Form_codebook.pdf
- PL_Biochemistries - Procedural labs_codebook.pdf
- PQIA_PedsQL_Infant_1-12mo_codebook.pdf
- PQIB_PedsQL_Infant_13-24mo_codebook.pdf
- PQPF_PedsQL_English_Fatigue_PR_codebook.pdf
- PQPGB_PedsQL_English_Generic_PR_2-4_codebook.pdf
- PQPGC_PedsQL_English_Generic_PR_8-12_codebook.pdf

- PQPGT_PedsQL_English_Generic_PR_13-18_codebook.pdf
- PQPGY_PedsQL_English_Generic_PR_5-7_codebook.pdf
- PQSFC_PedsQL_English_Fatigue_SR_8-12_codebook.pdf
- PQSFT_PedsQL_English_Fatigue_SR_13-18_codebook.pdf
- PQSFY_PedsQL_English_Fatigue_SR_5-7_codebook.pdf
- PQSGC_PedsQL_English_Generic_SR_8-12_codebook.pdf
- PQSGT_PedsQL_English_Generic_SR_13-18_codebook.pdf
- PQSGY_PedsQL_English_Generic_SR_5-7_codebook.pdf
- PR_Procedures Log_codebook.pdf
- SE_Screening Evaluation_codebook.pdf
- SF_Summary Measures Form_codebook.pdf
- SM_Serologies-Maternal_codebook.pdf
- SP_Serologies-Patient_codebook.pdf
- TB_Teacher BRIEF_codebook.pdf
- UN_UNOS Log_codebook.pdf
- VI_Virals_codebook.pdf
- VR_Validity Rating Form_codebook.pdf

Data\Phase 3\Proc_Contents

- PALF_AI_proc contents.rtf
- PALF_BG_proc contents.rtf
- PALF_CD_proc contents.rtf
- PALF_CP_proc contents.rtf
- PALF_DG_proc contents.rtf
- PALF_EV_proc contents.rtf
- PALF_FP_proc contents.rtf
- PALF_GA_proc contents.rtf
- PALF_GC_proc contents.rtf
- PALF_IF_proc contents.rtf
- PALF_IN_proc contents.rtf
- PALF_LO_proc contents.rtf
- PALF_MD_proc contents.rtf
- PALF_MT_proc contents.rtf
- PALF_NE_proc contents.rtf
- PALF_OP_proc contents.rtf
- PALF_PA_proc contents.rtf
- PALF_PF_proc contents.rtf
- PALF_PI_proc contents.rtf
- PALF_PL_proc contents.rtf
- PALF_PQIA_proc contents.rtf
- PALF_PQIB_proc contents.rtf
- PALF_PQPF_proc contents.rtf
- PALF_PQPGB_proc contents.rtf
- PALF_PQPGC_proc contents.rtf

- PALF_PQPGT_proc contents.rtf
- PALF_PQPGY_proc contents.rtf
- PALF_PQSFC_proc contents.rtf
- PALF_PQSFT_proc contents.rtf
- PALF_PQSFY_proc contents.rtf
- PALF_PQSGC_proc contents.rtf
- PALF_PQSGT_proc contents.rtf
- PALF_PQSGY_proc contents.rtf
- PALF_PR_proc contents.rtf
- PALF_SE_proc contents.rtf
- PALF_SF_proc contents.rtf
- PALF_SM_proc contents.rtf
- PALF_SP_proc contents.rtf
- PALF_TB_proc contents.rtf
- PALF_UN_proc contents.rtf
- PALF_VI_proc contents.rtf
- PALF_VR_proc contents.rtf

Data\Phase 3\Results from external laboratories

- BRAIN_INJURY_BIOMARKERS.CSV
- brain_injury_biomarkers.sas7bdat
- INFLAMMATORY_BIOMARKERS.CSV
- inflammatory_biomarkers.sas7bdat
- LIVER_REGENERATION_BIOMARKERS.CSV
- liver_regeneration_biomarkers.sas7bdat
- NK_CELL_BIOMARKERS.CSV
- nk_cell_biomarkers.sas7bdat
- Results from External Laboratories Read Me File.pdf

Data\Phase 3\Results from external laboratories\PedsQL_Results

- PEDSQL_AGE13TO24M_12M_EVAL.CSV
- pedsql_age13to24m_12m_eval.sas7bdat
- PEDSQL_AGE13TO24M_6M_EVAL.CSV
- pedsql_age13to24m_6m_eval.sas7bdat
- PEDSQL_AGE1TO12M_12M_EVAL.CSV
- pedsql_age1to12m_12m_eval.sas7bdat
- PEDSQL_AGE1TO12M_6M_EVAL.CSV
- pedsql_age1to12m_6m_eval.sas7bdat
- PEDSQL_AGE GREATER 24M_12M_EVAL.CSV
- pedsql_agegreater24m_12m_eval.sas7bdat
- PEDSQL_AGE GREATER 24M_6M_EVAL.CSV
- pedsql_agegreater24m_6m_eval.sas7bdat

Data\Phase 3\Results from external laboratories\PedsQL_Results\Proc Contents

- PedsQL_age1to12m_6m_eval_proc contents.rtf
- PedsQL_age1to12m_12m_eval_proc contents.rtf
- PedsQL_age13to24m_6m_eval_proc contents.rtf
- PedsQL_age13to24m_12m_eval_proc contents.rtf
- PedsQL_agegreater24m_6m_eval_proc contents.rtf
- PedsQL_agegreater24m_12m_eval_proc contents.rtf

Data\Phase 3\Results from external laboratories\Proc Contents

- Brain_Injury_Biomarkers_proc contents.rtf
- Inflammatory_Biomarkers_proc contents.rtf
- Liver_Regeneration_Biomarkers_proc contents.rtf
- NK_Cell_Biomarkers_proc contents.rtf

Documents

The PALF Documents directory contains:

- PALF Archive Read Me File.pdf
- PALF Study Bibliography.pdf

Documents\Phase 1

- PALF Phase I Protocol.pdf
- Pediatric Operations Man Jan 1 2001.pdf

Documents\Phase 2

- PALF NAC Site Protocol v2.4.pdf
- PALF Registry Site Protocol v2.6.pdf

Documents\Phase 3

- PALF Cohort Study Protocol and Appendix_2014.03.10.pdf
- PALF Public Website URL.pdf

DSIC

The PALF Dataset Integrity Check (DSIC) directory contains:

- PALF_DSIC.pdf

Forms

The PALF Forms directory contains:

Forms\Phase 1\NAC

- NAC Follow-up Form.pdf
- NAC Form.pdf

Forms\Phase 1\Registry

- Admission Form.pdf
- Outcome Form.pdf

Forms\Phase 2\NAC

- NC_NAC Trial Criteria.pdf
- NC_NAC form.pdf

Forms\Phase 2\NAC\Form Completion Documents

- NC_NAC Trial Criteria_QbyQ.pdf
- NC_NAC form_QbyQ.pdf

Forms\Phase 2\Registry

- EL_Enrollment Log.pdf
- FF_Follow-up Form.pdf
- FV_Follow-up Vial Status.pdf
- HE_Hospitalization Evaluation.pdf
- HF_Hospitalization Flowsheet.pdf
- RC_Registry Criteria.pdf
- SC_Sample Collection Checklist.pdf

Forms\Phase 2\Registry\Form Completion Documents

- EL_Enrollment Log_QbyQ.pdf
- FF_Follow-up Form_QbyQ.pdf
- FV_Follow-up Vial Status_QbyQ.pdf
- HE_Hospitalization Evaluation_QbyQ.pdf
- HF_Hospitalization Flowsheet_QbyQ.pdf
- RC_Registry Criteria_QbyQ.pdf

Forms\Phase 3

- AI_Autoimmune.pdf
- BG_Biochemistries - Blood Gases.pdf
- CD_Biochemistries - CBC with Differential.pdf
- CP_Biochemistries - Comprehensive Panel.pdf
- DG_Diagnosis Log.pdf
- EV_Event Log.pdf
- FP_Follow-up Form.pdf
- GA_Global Assessment.pdf
- GC_Genetics Consent.pdf
- IF_Infections.pdf
- IN_Intervention Log.pdf
- LO_Liver Offer Log.pdf
- MD_Medication Log.pdf
- MT_Metabolics.pdf
- NE_Neurocognitive Criteria.pdf
- OP_Off_Protocol.pdf
- PA_Physical Assessment.pdf
- PF_Patient Information Form.pdf

- PI_Patient Initialization Form.pdf
- PL_Biochemistries - Procedural labs.pdf
- PQIA_PedsQL_Infant_1-12mo.pdf
- PQIB_PedsQL_Infant_13-24mo.pdf
- PQQF_PedsQL_English_Fatigue_PR.pdf
- PQQGB_PedsQL_English_Generic_PR_2-4.pdf
- PQQGC_PedsQL_English_Generic_PR_8-12.pdf
- PQQGT_PedsQL_English_Generic_PR_13-18.pdf
- PQQGY_PedsQL_English_Generic_PR_5-7.pdf
- PQSFC_PedsQL_English_Fatigue_SR_8-12.pdf
- PQSFT_PedsQL_English_Fatigue_SR_13-18.pdf
- PQSFY_PedsQL_English_Fatigue_SR_5-7.pdf
- PQSGC_PedsQL_English_Generic_SR_8-12.pdf
- PQSGT_PedsQL_English_Generic_SR_13-18.pdf
- PQSGY_PedsQL_English_Generic_SR_5-7.pdf
- PR_Procedures Log.pdf
- SE_Screening Evaluation.pdf
- SF_Summary Measures Form.pdf
- SM_Serologies-Maternal.pdf
- SP_Serologies-Patient.pdf
- TB_Teacher BRIEF.pdf
- UN_UNOS Log.pdf
- VI_Virals.pdf
- VR_Validity Rating Form.pdf

Forms\Phase 3\Phase Completion Documents

- AI_Autoimmune_QbyQ.pdf
- Biochemistries_QbyQ.pdf
- Data Collection Flowsheet.pdf
- Data Collection Timeline.pdf
- DG_Diagnosis Log_QbyQ.pdf
- EV_Event Log_QbyQ.pdf
- FP_Follow-up Form_QbyQ.pdf
- GA_Global Assessment_QbyQ.pdf
- GC_Genetics Consent_QbyQ.pdf
- IF_Infections_QbyQ.pdf
- IN_Intervention Log_QbyQ.pdf
- LO_Liver Offer Log_QbyQ.pdf
- MD_Medication Log_QbyQ.pdf
- MT_Metabolics_QbyQ.pdf
- Neurocog.Longitudinal_MOP.pdf
- NE_Neurocognitive Criteria_QbyQ.pdf
- OP_Off_Protocol_QbyQ.pdf
- PA_Physical Assessment_QbyQ.pdf

- PedsQL_QbyQ.pdf
- PF_Patient Information Form_QbyQ.pdf
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- PR_Procedures Log_QbyQ.pdf
- SE_Screening Evaluation_QbyQ.pdf
- SP&SM_Serologies-Patient&Serologies-Maternal_QbyQ.pdf
- UN_UNOS Log_QbyQ.pdf
- VI_Virals_QbyQ.pdf

Forms\Phase 3\Phase Completion Documents\Data Management System

- PALF Data Management System Guide_v2.0.pdf
- Sample Tracking System Guide_v1.0.pdf