

Pediatric Acute Liver Failure

HOSPITALIZATION EVALUATION

04/01/2008
Version 1.3

FORM KEYS
Patient ID ____ - ____ - ____
Date enrolled ____ - ____ - ____
(mm-dd-yy)

COMPLETION LOG
Data Collector ID _____ Initials
Data Collection ____ - ____ - ____ **DDCM/DDCD/DDCY**
Date Entered ____ - ____ - ____
Date Verified ____ - ____ - ____
MM DD YY

SECTION I: DEMOGRAPHICS

1. Gender: Male Female **SEX**
2. Date of birth ____ - ____ - ____ **DOBM/DOBD/DOBY**
 (mm-dd-yyyy)

3. Is the patient Hispanic, Latino, or Latina? **HSP**
- No
- Yes →

3.1 Specify origin: **HSPO**

1 Cuban

2 Mexican

3 Puerto Rican

4 Other: _____ **HSPOS**

4. With what race does the patient most identify? (check all that apply)
- White or Caucasian **RACEW** American Indian or Alaska Native **RACAA**
- Black or African-American **RACEB** Native Hawaiian or other Pacific Islander **RACNP**
- Asian **RACEA** Other **RACEO** _____ **RACES**
5. Years of education completed: _____ N/A Un known **YRSED**
6. Number of siblings (full or half brothers/sisters): _____ **SIBL**

SECTION II: ADMISSION HISTORY

1. Initial hospital admission _____ - ____ - ____ **DOAM/DOAD/DOAY**
 (mm-dd-yy)

- 1a. Hospital transfer **HTRN** Yes No →
- Date of transfer: ____ - ____ - ____
HTRNM/HTRND/HTRNY (mm-dd-yy)

2. Date and time enrolled _____ - ____ - ____ _____ - ____ **ERLM/ERLD/ERLY ERLHR/ERLMN**
 (24-hour time)

3. Date of onset of jaundice _____ - ____ - ____ N/A, patient not jaundiced **JAUOM/JAUOD/JAUOY**
 (mm-dd-yy)

4. Current symptoms (since onset of 1st symptom)

	Yes	No	Unk		Yes	No	Unk
Nausea/vomit SYNAU	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Lethargy SYLET	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Abdominal pain SYABD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Malaise SYMAL	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rash SYRSH	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Fever SYFEV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seizure SYSEZ	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Other, specify SYO	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Altered consciousness SYCON	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____ SYOS			
Jaundice SYJAU	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				

5. Alcohol use? Yes No Unk **ALCUS**
6. Ecstasy use within 7 days of onset of symptoms? Yes No Unk **ECTUS**

SECTION III: SYSTEM REVIEW & FAMILY HISTORY

		Patient	Mother	Father/Extended Family	Sibling
1. Cardiomyopathy	CMYOP	Y N U	CMYOM Y N U	CMYOF Y N U	CMYOS Y N U
2. Cardiac arrhythmia	CARRP	Y N U	CARRM Y N U	CARRF Y N U	CARRS Y N U
3. Heart disease	HRTDP	Y N U	HRTDM Y N U	HRTDF Y N U	HRTDS Y N U
4. Seizure disorder	SEIZP	Y N U	SEIZM Y N U	SEIZF Y N U	SEIZS Y N U
5. Myopathy	MYOP	Y N U	MYOM Y N U	MYOF Y N U	MYOS Y N U
6. NASH (fatty liver)	NASHP	Y N U	NASHM Y N U	NASHF Y N U	NASHS Y N U
7. Malignancy	MLGP	Y N U	MLGM Y N U	MLGF Y N U	MLGS Y N U
8. Autoimmune disease	AUTIP	Y N U	AUTIM Y N U	AUTIF Y N U	AUTIS Y N U
9. Unexplained liver disease			ULVRM Y N U	ULVRF Y N U	ULVRS Y N U
10. Consanguinity			CSGM Y N U	CSGF Y N U	
11. HELLP syndrome			HELPM Y N U		
12. Severe pre-eclampsia			ECLPM Y N U		
13. AFLP			AFLPM Y N U		
14. SIDS					SIDS Y N U
15. Were maternal serologies performed?		<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unk	MSER

	Pos	Neg	ND	Unk		Pos	Neg	ND	Unk		
15.1 HepA IgM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	MHEPA	15.6 HepC Ab	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	MHEPC
15.2 HBsAg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	MHBSG	15.7 Toxo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	MTOXO
15.3 HBsAb	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	MHBSB	15.8 Rubella	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	MRUB
15.4 HBcAb	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	MHBCB	15.9 CMV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	MCMV
15.5 HBeAg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	MHBEG	15.10 Herpes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	MHERP

SECTION IV: MEDICATIONS

1. Drugs taken within last 6 months (check all that apply):

		Yes	No	Unk		Yes	No	Unk
Anesthetics	MXAST	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Immunosuppressives	MXIMM	<input type="checkbox"/>	<input type="checkbox"/>
Anti TB agents	MXTB	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NSAIDS	MXNSD	<input type="checkbox"/>	<input type="checkbox"/>
Antibiotics	MXABT	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	OTC	MXOTC	<input type="checkbox"/>	<input type="checkbox"/>
Anticonvulsants	MXCNV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Psychiatric	MXPSY	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes meds	MXDIB	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Vitamins/nutritional sup.	MXVIT	<input type="checkbox"/>	<input type="checkbox"/>
Estrogens	MXEST	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Other, specify	MXO	<input type="checkbox"/>	<input type="checkbox"/>
Herbals	MXHRB	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	MXOS		

2. Medications in last 1 month (include toxins, herbs, mushrooms, OTC meds, vitamins, anesthetics)

Medication/Toxin Name		Office Use	Date last taken	Total Daily Dose		Duration	
1	MEDN1	MEDC1 --	LDM1/LDD1/LDY1	TDD1 _____	<input type="checkbox"/> mg TDDU1	DUR1 ___	<input type="checkbox"/> days DURP1
2	MEDN2	MEDC2 —	LDM2/LDD2/LDY2	TDD2 _____	<input type="checkbox"/> mg TDDU2	DUR2_	<input type="checkbox"/> days DURP2
3	MEDN3	MEDC3_	LDM3/LDD3/LDY3	TDD3_____	<input type="checkbox"/> mg TDDU3	DUR3_	<input type="checkbox"/> days DURP3
4	MEDN4	MEDC4_	LDM4/LDD4/LDY4	TDD4_____	<input type="checkbox"/> mg TDDU4	DUR4_	<input type="checkbox"/> days DURP4
5	MEDN5	MEDC5_	LDM5/LDD5/LDY5	TDD5_____	<input type="checkbox"/> mg TDDU5	DUR5_	<input type="checkbox"/> days DURP5
6	MEDN6	MEDC6_	LDM6/LDD6/LDY6	TDD6_____	<input type="checkbox"/> mg TDDU6	DUR6_	<input type="checkbox"/> days DURP6
7	MEDN7	MEDC7 —	LDM7/LDD7/LDY7	TDD7_____	<input type="checkbox"/> mg TDDU7	DUR7_	<input type="checkbox"/> days DURP7
8	MEDN8	MEDC6_	LDM8/LDD8/LDY8	TDD8_____	<input type="checkbox"/> mg TDDU8	DUR8_	<input type="checkbox"/> days DURP8
9	MEDN9	MEDC9_	LDM9/LDD9/LDY9	TDD9_____	<input type="checkbox"/> mg TDDU9	DUR9_	<input type="checkbox"/> days DURP9

Medication variables repeat through 27

3. Acetaminophen use? Yes No ACUS

<p>3.1 Amount taken: ACAMT</p> <p><input type="checkbox"/> Single dose →</p> <p><input type="checkbox"/> Chronic use →</p> <p>3.2 Acetaminophen toxicity: ACDOS</p> <p><input type="checkbox"/> Suicide attempt</p> <p><input type="checkbox"/> Accidental overdose</p> <p><input type="checkbox"/> Unknown</p> <p><input type="checkbox"/> N/A</p>	<p>3.1.1 Total dose: _____ mg STD</p> <p>3.1.2 Date taken: ____ - ____ - ____ STDM/STDD/STDY</p> <p>3.1.3 Time taken: ____ : ____ STDHR: STDMN</p> <hr/> <p>3.1.4 Average daily dose _____ mg CTD</p> <p>3.1.5 Number of days taken: ____ CTDD</p> <p>3.1.6 Was a dose of >100 mg/kg taken during illness? <input type="checkbox"/> Yes <input type="checkbox"/> No CTDI</p> <p>3.1.7 Reason taken: CTDR</p> <p><input type="checkbox"/> Fever <input type="checkbox"/> Pain <input type="checkbox"/> Other _____ CTDRS</p>
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SECTION V: PHYSICAL EXAM (at time of enrollment in registry)

Height: HGTCM _____ cm

HGHT actual estimate

1 in = 2.54 cm

Pulse: HRMIN _____ beats/min

Weight: WGTKG _____ kgs

1 lb = 0.45 kg

Blood pressure: _____ / _____ mmHg BPS/BPD

Temperature: _____ °C

TEMPC

Hepatic coma grade: 0 I II III IV COMAG

PRISM score: _____ PRISM Date assessed: ____ - ____ - ____ not assessed PRSMM – PRSMD – PRSMY
(mm-dd-yy)

Does the patient have the following:

	<u>Yes</u>	<u>No</u>		<u>Yes</u>	<u>No</u>
Peripheral edema PEDM	<input type="checkbox"/>	<input type="checkbox"/>	Hepatomegaly HEPAT	<input type="checkbox"/>	<input type="checkbox"/>
Capillary refill > 2 secs CAPRF	<input type="checkbox"/>	<input type="checkbox"/>	Hyper-reflexia HRFLX	<input type="checkbox"/>	<input type="checkbox"/>
Splenomegaly SPLN	<input type="checkbox"/>	<input type="checkbox"/>	Pupillary dilatation PUPDL	<input type="checkbox"/>	<input type="checkbox"/>
Ascites ASCT	<input type="checkbox"/>	<input type="checkbox"/>	Delayed development DDEV	<input type="checkbox"/>	<input type="checkbox"/>
Jaundice JAUN	<input type="checkbox"/>	<input type="checkbox"/>			

SECTION VI: LABORATORY TESTS AND SEROLOGIES

Blood <i>Differential</i>	Not Done	Miscellaneous	Not Done
PMN PMN ___ %	<input type="checkbox"/>	Alpha-1-AT P _i type A1AT ___	<input type="checkbox"/>
Lymphocytes LYMP ___ %	<input type="checkbox"/>	Alpha-1-AT level A1AL _____ mg/dL	<input type="checkbox"/>
Eosinophils EOSIN ___ %	<input type="checkbox"/>	Serum copper CUS _____ µg/ml	<input type="checkbox"/>
Monos MONO ___ %	<input type="checkbox"/>	Urine copper CUU _____ µg/24 hr.	<input type="checkbox"/>
Kidney/Electrolytes		Ceruloplasmin CERP ___ mg/dL	<input type="checkbox"/>
Uric acid UA ___ . ___ mg/dL	<input type="checkbox"/>	Alpha-fetoprotein AFP _____ ng/ml	<input type="checkbox"/>
Urine ketones (degree of positivity) UK - + ++ +++ +++++	<input type="checkbox"/>	Ferritin FERR _____ ng/ml	<input type="checkbox"/>
		Serum iron SFE _____ µg/dL	<input type="checkbox"/>
Liver		T ₄ T4 _____ µg/dL	<input type="checkbox"/>
Factor VII FVII ___ %	<input type="checkbox"/>	TSH TSH _____ IU/ml	<input type="checkbox"/>
Factor V FV ___ %	<input type="checkbox"/>	Cortisol CORT ___ . ___ µg/dL	<input type="checkbox"/>
Alk Phos ALP _____ IU/L	<input type="checkbox"/>	SLA IgG antibody SLAG ___ . ___ units	<input type="checkbox"/>
Total protein TP ___ . ___ gm/dL	<input type="checkbox"/>	IgG quantitative IGG _____ mg/dL	<input type="checkbox"/>
Amylase AMY _____ IU/L	<input type="checkbox"/>	Serologies Pos Neg	Not Done
CK CK _____ IU/L	<input type="checkbox"/>	Anti-HAV IgM HAVR <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>
Arterial/Toxins		HBsAg HBSAR <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>
St. BC STBC ___ . ___ mEq/L	<input type="checkbox"/>	Anti-HBc HBCR <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>
Urine for heavy metals? UHM <input type="checkbox"/> Pos <input type="checkbox"/> Neg	<input type="checkbox"/>	Anti-HBc IgM HBCMR <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>
Urine toxin screen? UTSC <input type="checkbox"/> Pos <input type="checkbox"/> Neg	<input type="checkbox"/>	HBeAg HBER <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>
If positive, indicate _____ UTSCS		Anti-HBs HBSR <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>
Acetaminophen level ACTL _____ mg/L	<input type="checkbox"/>	HBV-DNA HBVDR <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>
Miscellaneous Pos Neg	<input type="checkbox"/>	Anti-HDV HDVR <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>
Anti-smooth muscle ASMA <input type="checkbox"/> <input type="checkbox"/> 1:___ ASMAT	<input type="checkbox"/>	Anti-HCV HCVR <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>
ANA ANA <input type="checkbox"/> <input type="checkbox"/> 1:___ ANAT	<input type="checkbox"/>	HCV-RNA HCVRR <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>
pANCA PANCA <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	Anti-HEV HEVR <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>
Anti-LKM ALKM <input type="checkbox"/> <input type="checkbox"/> 1:___ ALKMT	<input type="checkbox"/>	Anti-HIV HIVR <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>
		B-Hcg BHCGR <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>

SECTION VII: VIRAL STUDIES (if positive result, record Source code)

Infectious Disease	Culture				Antigen				Antibody (IgM)				PCR				Hybridization			
Adenovirus	ADOC	ADOC	ADOC	ADOC	ADOG	ADOG	ADOG	ADOG	ADOB	ADOB	ADOB	ADOB	ADOP	ADOP	ADOP	ADOP	ADOH	ADOH	ADOH	ADOH
Paramyxovirus	PMYC	PMYC	PMYC	PMYC	PMYG	PMYG	PMYG	PMYG	PMYB	PMYB	PMYB	PMYB	PMYP	PMYP	PMYP	PMYP	PMYH	PMYH	PMYH	PMYH
Herpes simplex	HSVC	HSVC	HSVC	HSVC	HSVG	HSVG	HSVG	HSVG	HSVB	HSVB	HSVB	HSVB	HSVP	HSVP	HSVP	HSVP	HSVH	HSVH	HSVH	HSVH
HHV-6	HHVC	HHVC	HHVC	HHVC	HHVG	HHVG	HHVG	HHVG	HHVB	HHVB	HHVB	HHVB	HHVP	HHVP	HHVP	HHVP	HHVH	HHVH	HHVH	HHVH
CMV	CMVC	CMVC	CMVC	CMVC	CMVG	CMVG	CMVG	CMVG	CMVB	CMVB	CMVB	CMVB	CMVP	CMVP	CMVP	CMVP	CMVH	CMVH	CMVH	CMVH
EBV	EBVC	EBVC	EBVC	EBVC	EBVG	EBVG	EBVG	EBVG	EBVB	EBVB	EBVB	EBVB	EBVP	EBVP	EBVP	EBVP	EBVH	EBVH	EBVH	EBVH
Parvovirus	PARC	PARC	PARC	PARC	PARG	PARG	PARG	PARG	PARB	PARB	PARB	PARB	PARP	PARP	PARP	PARP	PARH	PARH	PARH	PARH
ECHO virus	ECOC	ECOC	ECOC	ECOC	ECOG	ECOG	ECOG	ECOG	ECOB	ECOB	ECOB	ECOB	ECOP	ECOP	ECOP	ECOP	ECOH	ECOH	ECOH	ECOH
Other _____ OV1S	OV1C	OV1C	OV1C	OV1C	OV1G	OV1G	OV1G	OV1G	OV1B	OV1B	OV1B	OV1B	OV1P	OV1P	OV1P	OV1P	OV1H	OV1H	OV1H	OV1H
Other _____ OV2S	OV2C	OV2C	OV2C	OV2C	OV2G	OV2G	OV2G	OV2G	OV2B	OV2B	OV2B	OV2B	OV2P	OV2P	OV2P	OV2P	OV2H	OV2H	OV2H	OV2H

Source codes: 1=blood 2=tracheal aspirate 3=urine 4=liver tissue 5=stool 6=naso-pharyngeal

SECTION VIII: INFECTIONS (Record all positive cultures and date of first positive sample)

Site	Date 1 st positive	S	S epid	S pneum	E coli	Klebsie	Fungus	Other	Outcome (Resolved or Continuing)
Blood RID	BLDM/BLDD/BLDY	BLDSA	BLDSE	BLDSP	BLDEC	BLDK	BLDF	BLDO BLDOS	BLDOT
Trach TA	TAM/TAD/TAY	TASA	TASE	TASP	TAEC	TAK	TAF	TAO TAOS	TAOT
Urine UR	URM/URD/URY	URSA	URSE	URSP	UREC	URK	URF	URO UROS	UROT
Catheters CTH	CTHM/CTHD/CTHY	CTHSA	CTHSE	CTHSP	CTHEC	CTHK	CTHF	CTHO CTHOS	CTHOT
Wounds WND	WNDM/WNDD/ WNDY	WNSA	WNSE	WNDS	WNDEC	WNDK	WNDF	WNDO WNDS	WNDOT
Ascites ASC	ASCM/ASCD/ASCY	ASCSA	ASCSE	ASCSP	ASCEC	ASCK	ASCF	ASCO ASCOS	ASCOT

Anti-microbials Used	Antimicrobial code	Prophylaxis	Bowel Decontamination	Infection Therapy
MCRN1 _____	MCRC1	<input type="checkbox"/> MCRP1	<input type="checkbox"/> MCRB1	<input type="checkbox"/> MCR11
MCRN2 _____	MCRC2	<input type="checkbox"/> MCRP2	<input type="checkbox"/> MCRB2	<input type="checkbox"/> MCR12
MCRN3 _____	MCRC3	<input type="checkbox"/> MCRP3	<input type="checkbox"/> MCRB3	<input type="checkbox"/> MCR13
MCRN4 _____	MCRC4	<input type="checkbox"/> MCRP4	<input type="checkbox"/> MCRB4	<input type="checkbox"/> MCR14
MCRN5 _____	MCRC5	<input type="checkbox"/> MCRP5	<input type="checkbox"/> MCRB5	<input type="checkbox"/> MCR15
MCRN6 _____	MCRC6	<input type="checkbox"/> MCRP6	<input type="checkbox"/> MCRB6	<input type="checkbox"/> MCR16

SECTION IX: METABOLIC STUDIES

		Abnormal, Diagnostic	Abnormal, Nonspecific	Normal	Not Done
Urine organic acids	UOAR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Serum amino acids	SAAR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urine reducing substances	URSR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skin fibroblasts	SFBR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bile acid profile	BAPR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Galactosemia screen	GLSR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acylcarnitine profile	ACYR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urine succinylacetone	USCR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mitochondrial studies	MTOR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Glycogen storage disease	GSDR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other _____	MTO1S MT0R1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION X: SCANS, MONITORING, LIVER BIOPSY

Test	Date Performed	Findings
<input type="checkbox"/> CT or MR of brain CTB	____-____-____ CTBM/CTBD/CTBY	<input type="checkbox"/> Normal CTBNL <input type="checkbox"/> Hemorrhage CTBHM <input type="checkbox"/> Herniation CTBHR <input type="checkbox"/> Edema CTBED <input type="checkbox"/> Other CTBO ----- CTBOS
<input type="checkbox"/> CT of abdomen CTA	____-____-____ CTAM/CTAD/CTAY	<input type="checkbox"/> Normal CTANL <input type="checkbox"/> Ascites CTAAS <input type="checkbox"/> Inhomogenous CTAIH <input type="checkbox"/> Other CTAO _____ CTAOS
<input type="checkbox"/> Ultrasound of abdomen USA	____-____-____ USAM/UASD/USAY	<input type="checkbox"/> Normal USANL <input type="checkbox"/> Ascites USAAS <input type="checkbox"/> Hypoechoic liver USAHL Doppler performed? <input type="checkbox"/> Yes <input type="checkbox"/> No USADP <input type="checkbox"/> Other USAO If Yes, <input type="checkbox"/> Patent with normal flow USADR USAOS <input type="checkbox"/> Patent with reverse flow <input type="checkbox"/> Vessel occluded
<input type="checkbox"/> EEG EEG	EEGM/EEGD/EEGY	<input type="checkbox"/> Normal EEGNL <input type="checkbox"/> Seizure EEGSZ <input type="checkbox"/> Slowing EEGSL <input type="checkbox"/> Other EEGO _____ EEGOS
<input type="checkbox"/> Liver biopsy LBX <div style="border: 1px solid black; padding: 5px; margin-top: 5px;"> Electron Microscopy LBXEM <input type="checkbox"/> Yes <input type="checkbox"/> No Method: LBXMT <input type="checkbox"/> Needle <input type="checkbox"/> Transjugular <input type="checkbox"/> Wedge (surgery) </div>	____-____-____ LBXM/LBXD/LBXY	<input type="checkbox"/> Steatosis LBXST <input type="checkbox"/> Giant cell hepatitis LBXGH <input type="checkbox"/> Necrosis → <input type="checkbox"/> Panlobular LBXNP <input type="checkbox"/> Centrilobular LBXNC LBXN <input type="checkbox"/> Focal LBXNF <input type="checkbox"/> Fibrosis → <input type="checkbox"/> Portal LBXFP <input type="checkbox"/> Cirrhosis LBXFC LBXF <input type="checkbox"/> Bridging LBXFB → <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Other LBXO _____ LBXOS
<input type="checkbox"/> Skin biopsy SBX	____-____-____ SBXM/SBXD/SBXY	<input type="checkbox"/> Normal <input type="checkbox"/> Diagnostic <input type="checkbox"/> Not diagnostic <input type="checkbox"/> Other _____ SBXNL SBXDG SBXND SBXO SBXOS
<input type="checkbox"/> Muscle biopsy MBX	____-____-____ MBXM/MBXD/MBXY	<input type="checkbox"/> Normal <input type="checkbox"/> Diagnostic <input type="checkbox"/> Not diagnostic <input type="checkbox"/> Other _____ MBXNL MBXDG MBXND MBXO MBXOS
<input type="checkbox"/> Bone marrow biopsy BBX	____-____-____ BBXM/BBXD/BBXY	<input type="checkbox"/> Normal <input type="checkbox"/> Diagnostic <input type="checkbox"/> Not diagnostic <input type="checkbox"/> Other _____ BBXNL BBXDG BBXND BBXO BBXOS

SECTION XI: LIST STATUS

1. Ever listed for transplant: **LXTP**

Yes →

1.1 Date of initial listing: ____-____-____ (mm-dd-yy) **LXML/XD/LXY** ____

1.2 UNOS status at listing: **LXST** MELD/PELD score ____ **MELD**

1.3 Currently listed: **LXCUR**

Yes →

Current UNOS status: ____ **CUST**

MELD/PELD score **MELDC**

No →

Date removed from list ____ - ____ - ____

RLXM/RLXD/RLXY

Primary reason removed from list (check one): **RLXR**

Improved Irreversible brain damage

Sepsis Medically unsuitable

Other _____ **RLXRS**

No →

1.4 Primary reason not listed (check one): **NOLXT**

Not sick enough, too well Irreversible brain damage

Sepsis Active substance abuse

Inadequate social support Active psychiatric disease

Medically unsuitable Other _____ **NLXOS**

SECTION XII: OUTCOME (at time of hospital discharge, transplant, or death)

1. Hospital discharge **DSC** →

1.1 Date of discharge: ____ - ____ - ____ **DSCM/DSCD/DSCY**

1.2 Location of patient: **DSCLC**

Home

Not home, specify location _____ **DSCLS**

2. Transplant **TRP** →

2.1 Date of transplant: ____ - ____ - ____ **TRPM/TRPD/TRPY**

2.2 Type of transplant (check one): **TRPT**

Whole Auxiliary Reduced Split liver

Living-related Hepatocyte Other _____ **TRPTS**

2.3 ABO compatible liver? Yes No **ABOC**

2.4 Resected liver weight: _____ gm **RLVWT**

2.5 Resected liver histology (check all that apply)

Necrosis **RLVNC** Fibrosis **RLVFB** Inflammation **RLVIF**

Steatosis **RLVSS** Storage **RLVST**

3. Died **DEATH** →

3.1 Date of death: ____ - ____ - ____ **DODM/DODD/DODY**

3.2 Major underlying cause of death: _____ (see codebook) **COD CODS**

3.3 Autopsy performed: Yes No **AUTOP**

Was parent/guardian approached to obtain consent to collect registry samples at time of autopsy? Yes No **AUTAC**

Was consent obtained? Yes No **AUTOB**

SECTION XIII: DIAGNOSIS

At Enrollment (check one) **DIAG**

- Acetaminophen
- Shock/ischemia
- Metabolic liver disease

- Budd-Chiari
- Neonatal iron storage disease

- Hemophagocytic syndrome
- Veno-occlusive disease

- Respiratory chain deficit
- Wilson's disease
- Alpha-1-antitrypsin
- Other _____ **IMLDS**

- Tyrosinemia
- Fatty acid oxidation _____ **IFAOS**
- Mitochondrial _____ **IMTCS**

Hepatitis

- Viral:
 - A B (±delta) C E EBV CMV Herpes simplex
 - Other _____ **IOTHS**
- Autoimmune
- Drug-induced, agent _____ **IDRGA**

- Other _____ **IDXOS**
- Indeterminate

Final (check all that apply)

- Acetaminophen **ACET**
- Shock/ischemia **SHCK**
- Metabolic liver disease **MTLD**

- Budd-Chiari **BUDC**
- Neonatal iron storage disease **NISD**

- Hemophagocytic syndrome **HPHGS**
- Veno-occlusive disease **VENO**

- Respiratory chain deficit **RCD**
- Wilson's disease **WILS**
- Alpha-1-antitrypsin **A1TRY**
- Other **MTLDO MTLDS** _____

- Tyrosinemia **TYRO**
- Fatty acid oxidation **FAO** _____ **FAOS**
- Mitochondrial **MTOC** _____ **MTOCS**

Hepatitis

HEP

- Viral:
 - A B (±delta) C E EBV CMV Herpes simplex
 - Other **HOTH HOTH**
- Autoimmune **HAUTO**
- Drug-induced, agent **HDRG** _____ **HDRGA**

- Other **FDXO** _____ **FDXOS**
- Indeterminate **FDXID**

SECTION XIV: COMMENTS: Yes No **COMM**

IF YES
COMM1-5
