

Initial History HARMONIZATION (2020)

Calculated Fields

2

Hidden Protocol Question

- BASIC
- MITOHEP
- LOGIC
- PROBE
- FORCE

3

Hidden visit question

- Baseline
- Follow-up
- Transplant

4

Hidden Disease Question

- BA
- PFIC
- ALGS
- A1AT
- BAD
- MITO
- Other non-BA

5

Hidden Age Question

A. Procedures

A1

Was a drainage procedure performed on this participant?

- No
- Yes

A2

Kasai?

Kasai date

- No
- Yes

07 16 2020
MM DD YYYY
Today

A3

Kasai revision?

- No
- Yes

Kasai revision date

07 16 2020
MM DD YYYY
Today

A4

Partial external biliary diversion?

- No
- Yes

Date:

07 16 2020
MM DD YYYY
Today

A5

Ileal exclusion?

- No
- Yes

Date:

07 16 2020
MM DD YYYY
Today

A6

Cholecystectomy?

- No
- Yes

Date:

07 16 2020
MM DD YYYY
Today

A7

Gallstones present?

- No
- Yes

A8

Was another drainage procedure performed? If Yes, please specify:

- No
- Yes (specify):

Date:

07 16 2020
MM DD YYYY
Today

A9

Liver transplantation

- No
- Yes

Transplant date:

07	16	2020
MM	DD	YYYY
Today		

B. Clinical History

B1

When did you first notice that your child had symptoms of liver disease (eg, jaundice, pruritis, splenomegaly, bruising, etc.)? (month/year)

07	16	2020	Today
MM	DD	YYYY	

B2

Has the diagnosis of mitochondrial liver disease been made?

- No
- Yes
- Don't Know

If yes, when?

07	16	2020
MM	DD	YYYY
Today		

Has the participant ever been diagnosed with...?

B3

Clinically evident ascites requiring treatment with diuretics after 6 months of age

- No
- Yes

Date first diagnosed

07	16
MM	DD
2020	Today
YYYY	

B4

Hepatopulmonary Syndrome (HPS)

- No
- Yes
- Unknown

B5

Hepatorenal syndrome

- No
- Yes
- Unknown

B6

Gallstones

- No
- Yes
- Unknown

B7

Persistent or Chronic Diarrhea, lasting for more than 6 months

- No
- Yes
- Unknown

B8

Pancreatitis

- No
- Yes
- Unknown

B9

Has the participant ever been screened for varices with an upper endoscopy?

- No
- Yes
- Unknown

B10

Esophageal varices detected

- No
- Yes
- Unknown

B11

Gastric varices detected

- No
- Yes
- Unknown

C. Genetic Relatives

C1

Is this participant genetically related to a previously enrolled participant in ChiLDReN?

- No

Yes

C2

List all genetic relatives previously enrolled in ChiLDRen
You haven't defined a grid for this can-grow
