Please fax or mail to: FAP-World Transplant Register, Department of Transplantation Surgery F82, Karolinska University Hospital Huddinge, S-141 86 Stockholm, Sweden. Fax nr +46 8 774 31 91 **E-mail: fapwtr@fapwtr.org Web site: www.fapwtr.org**

Liver Transplantation for FAP – world register

Guidelines
- Liver transplantation for FAP
- Transplantation of kidney or heart
- Patient death

FORM 1 – INITIAL REPORT

(Please use one page for each patient)

Name and location of tx center:_____

Date of report ___ ___ ___
D M Y

Contact person & title:_____

Register use only

FAPWTR: M ☐

Pat key: A ☐

Pat.id.

Pat id ___ ___ ___ ___ ___ ___
(Given name) first letters (Family name) first letters

Born ___ ___ ___ or Age:_____
D M Y

Male ☐

Female ☐

Race:_____ Nationality:_____

Donor

Necrodonor ☐ Living related donor ☐

Liver tx

Date of LTX ___ ___ ___
D M Y

Domino: Yes ☐ No ☐ (FAP liver to another patient)

If yes: Fap liver to other transplantation center?

Assoc. tx

Renal tx: Yes ☐ No ☐ Date ___ ___ ___
D M Y

Cardiac tx: Yes ☐ No ☐ Date ___ ___ ___
D M Y

Yes ☐ No ☐
If yes, please specify:

Hospital:_____

_____

City:_____

Country:_____

Contact person:_____

_____

Outcome

Alive? Yes ☐ No ☐ Date of death ___ ___ ___
D M Y

Cause of death:_____

TTR

TTR-mutation: MET-30 ☐ Other ☐ Please specify:_____

MBMI

PreOLT body weight:_____kg Height:_____m Serum albumin:_____units (Ref. value:_____)

Clinical manifestations pre LTX

PERIPHERAL NEUROPATHY	Yes	No
* sensory……..	☐	☐
* motor…….	☐	☐
CRANIAL NEUROPATHY	☐	☐
AUTONOMIC NEUROPATHY		
* digestive……..	☐	☐
* urinary…….	☐	☐
* sexual dysfunction……..	☐	☐
* cardiovascular…….	☐	☐

EXTRANEUROLOGIC AMYLOIDOSIS	Yes	No
* renal……	☐	☐
* ocular……..	☐	☐
* cardiac……	☐	☐
MALNUTRITION……	☐	☐
PSYCHIATRIC DISTURBANCES…….	☐	☐

DURATION OF SYMPTOMS BEFORE TX_____years

INITIAL SYMPTOM:_____

HEREDITY: Yes ☐ Please specify_____
Maternal ☐ Paternal ☐
No ☐ Unknown ☐