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)

Date of report: ___ ___ ___
D M Y

Name and location of TX center: ____________________

Contact person & Title: ____________________

Register use only

FAPWTR:

Pat key:

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

Born ___ ___ ___ (D M Y)

Nationality ____________

Male ☐

Female ☐

Date of LTX ___ ___ ___ (D M Y)

Deceased donor ☐ Living related donor ☐ Domino: Yes ☐ No ☐ (FAP liver to another patient)

If the FAP liver was sent to another center, please specify:

Hospital: ____________ City: ____________ Country: ____________

Contact information: ____________________

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

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

Alive: Yes ☐ No ☐ Date of death ___ ___ ___ (D M Y)

Cause of death: ____________________

TTR mutation: Val30Met ☐ Other ☐

If other, please specify: ____________________

At time of tx: 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	☐	☐

EXTRANEUROLOGICAL AMYLOIDOSIS	Yes	No
• Renal	☐	☐
• Ocular	☐	☐
• Cardiac	☐	☐
MALNUTRITION	☐	☐

Duration of FAP symptoms before tx (years): __________

Initial FAP symptom: ____________________

____

Heredity: Maternal ☐ Paternal ☐ Unknown ☐ No ☐

Pharmacotherapy for FAP - before LTX

Pharmacotherapy pre tx, any time: Yes ☐ No ☐ No info ☐

If yes:	Started (mm/yy)	Ongoing until Ltx Yes	No	If no, discont. (mm/yy)	Reason for end of medication
Tafamidis	___/___	☐	☐	___/___	____________________
Diflunisal	___/___	☐	☐	___/___	____________________
TUDCA+Tetracycline	___/___	☐	☐	___/___	____________________
Other	___/___	☐	☐	___/___	____________________

If Other, specify: ____________________

	Yes	No
LTx due to disease progress during pharmacotherapy?	☐	☐
Pharmacotherapy only while waiting for LTx to halt progress?	☐	☐
Pharmacotherapy planned to continue after LTx?	☐	☐