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**

Guidelines
- Liver retransplantation
- Transplantation of kidney or heart
- Patient death
- Patient lost to follow-up
- YEARLY FOLLOW-UP

Liver Transplantation for FAP – world register

FORM 2 – UPDATE
(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) Alive: Yes ☐ No ☐ Date of death ___ ___ ___ (D M Y) Cause of death: _____

Re-LTX (1): No ☐ Yes ☐ Date ___ ___ ___ (D M Y) Cause of Re-LTX (1): _____

Re-LTX (2): No ☐ Yes ☐ Date ___ ___ ___ (D M Y) Cause of Re-LTX (1): _____

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

Body weight: _____ kg Height: _____ m Serum albumin: _____ units (Ref value: _____)

Clinical condition compared to pre-transplant

	Improved	Unchanged	Progressed
PERIPHERAL NEUROPATHY			
• Sensory	☐	☐	☐
• Motor	☐	☐	☐
AUTONOMIC NEUROPATHY			
• Digestive	☐	☐	☐
• Urinary	☐	☐	☐
• Sexual dysfunction	☐	☐	☐
• Cardiovascular	☐	☐	☐

	Improved	Unchanged	Progressed
EXTRANEUROLOGICAL AMYLOIDOSIS			
• Renal	☐	☐	☐
• Ocular	☐	☐	☐
• Cardiac	☐	☐	☐
NUTRITION	☐	☐	☐

Pharmacotherapy for FAP - Before LTX

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

If yes:	Started (mm/yy)	Ongoing until Ltx Yes	Ongoing until Ltx 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?	☐	☐

Pharmacotherapy for FAP - After LTX

Pharmacotherapy: Yes ☐ No ☐ No info ☐

If yes:	Started (mm/yy)	Discont. (mm/yy)	Reason for start/end of medication
Tafamidis	___/___	___/___	_____
Diflunisal	___/___	___/___	_____
TUDCA+Tetracycline	___/___	___/___	_____
Other	___/___	___/___	_____

If Other, specify: _____