



Attention - DO NOT enter patient data on this form if the header does not contain *preprinted* HALT PKD ID number, clinical center ID, and visit number.

Participant ID: _____ *haltid* Clinical Center: _____ *clinic* Date of Visit: ____/____/____
month *dvm* day *dvd* year *dvy*

visit: _____

___ Form was not completed *misfm*

POST-CLOSEOUT FOLLOW-UP (STUDY A)

Form # 52

This form is to be completed when ESRD is determined and annually on Study A participants who have closed out of the study. The form should be updated every twelve months until end of study or death has occurred.

NOTE: ESRD is defined as the start of hemodialysis, peritoneal dialysis or kidney transplantation, at the discretion of the subject's primary nephrologist.

Please document the date the last study medication was stopped. ____/____/____
dtcdm dm dtcdm dd dtcdm dy

- 1 Participant agreed to post-closeout follow up (please complete the appropriate sections below).
- 2 Participant declined post-closeout follow up (this form need not be completed again).
- 3 Participant deceased (please complete section D of this form and also complete form 31). *partcat*

Please document endpoint reached at this point of contact. *endpt*

- 1 Neither ESRD nor Death reached (Complete Section A & STOP)
- 2 ESRD – Treated with Dialysis (Complete Section B & STOP)
- 3 ESRD – Treated with a Kidney Transplant (Complete Section C & STOP)

A. ESRD or Death not Reached

Current Serum Creatinine Date *screatdt*

____/____/____

Current serum creatinine value _____ mg/dL *cursercr*
(Enter the **confirmatory** sample value)

Serum Creatinine sample was obtained at: *screlab*

- 1 PCC and shipped to Cleveland Clinic Lab for analysis
- 2 Quest
- 3 Other Lab that uses IDMS traceable standard for serum creatinine measurement
- 4 Other Lab (serum creatinine assay unknown)

B. ESRD – treated with dialysis

Date of First Chronic Dialysis *esrdddt*

____/____/____

Current Type of Dialysis: *dialstyp*

- 1 Hemodialysis
- 2 Peritoneal Dialysis
- 3 Other Specify: *dialtpsp* _____

Has a nephrectomy been performed? *neph*

- 1 Yes If YES, 4 Left partial 5 Left full 6 Right partial 7 Right full 3 Unknown *nephyes*
- 0 No

Most recent serum creatinine value prior to start of dialysis _____ mg/dL *recsercr*
(ASK ONCE, first time completing this section)

PCC has received a lab report confirming the above serum creatinine? *pccnfsc* 0 No 1 Yes
(ASK ONCE, first time completing this section)



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month *dvm* day *dvd* year *dvy*

visit: _____

____ Form was not completed *misfm*
Form # 52

POST-CLOSEOUT FOLLOW-UP (STUDY A)

C. ESRD – Treated with transplant

Date of the Kidney Transplant *esrdktdt*

□□ / □□ / □□□□

Type of kidney transplant: *kdntyp*

1 Deceased Donor Kidney Transplant

2 Living Donor Kidney Transplant

3 Other Specify: *kdntypsp* _____

Was a nephrectomy performed prior to kidney transplant? *nephprkd*
(ASK ONCE, first time answering YES to transplant)

1 Yes If YES, 4 Left partial 5 Left full 6 Right partial 7 Right full 3 Unknown *nphprkdis*
0 No

Was this a preemptive kidney transplant? *premkdtr* 0 No If NO, STOP 1 Yes
(ASK ONCE, first time answering YES to preemptive transplant)

Most recent serum creatinine value prior to preemptive transplant _____ mg/dL *sercrpremp*

PCC has received a lab report confirming the above serum creatinine? *rptscrpremp* 0 No 1 Yes
(ASK ONCE, first time completing this section)

D. Death

Date of Death *deathdt*

□□ / □□ / □□□□

Was death kidney related? *deatkidrel* 0 No 1 Yes

Was an autopsy performed? *deatautper* 0 No 1 Yes

Was the death certificate obtained? *deatcert* 0 No 1 Yes

Cause of Death *deathcaus* _____

Comments *comments* _____

HALT PKD staff member completing this form: _____ Date: ____ / ____ / ____
cmidnum Month *cdm* Day *cdd* Year *cdy*

Data Entry Status: Please check to indicate that the above information has been entered

Primary Entered by: _____ Date: ____ / ____ / ____
deidnum dem Month *ded* Day *dey* Year

Secondary Entered by: _____ Date ____ / ____ / ____