

## Notification of Transfer, Remote Site Collection, or Refusal to Participate

This form is used to document the transfer of GoKinD participants, refusal to participate, or the use of remote sites. When responsibility for the visit of a GoKinD participant needs to be transferred to another GoKinD clinic, the original GoKinD clinic staff should make the necessary arrangements. White copy of this form should be sent to the Coordinating Center, yellow copy to the new GoKinD clinic and retain pink copy at the original clinic.

## A. IDENTIFYING INFORMATION

- 1. Original GoKinD Clinic Number
- 2. Family ID Number

If the form applies to all members of the same family, check here and skip items 3 & 4. (Only for refusals to participate.) Complete separate forms for each proband/parent if transfer/remote site collection. (1)

- 3. Proband/Relative code
- 4. Proband/Relative Initials

FML

## **B. TRANSFER TO A NEW CLINIC**

- Check here to indicate participant transfer (1) to another GoKinD clinic.
- 2. Check here to indicate a remote site collection. (1)
- 3. Enter the clinic ID number of the new GoKinD clinic.
- 4. If the collection will be done at a remote site, enter the city and state of remote site:
  - City
- C. TRANSFER TO CTI, Network
  - Check here to indicate participant transfer (1) to another GoKinD clinic.

State

- Enter the clinic ID number of the consenting GoKinD clinic.
- 3. If the collection will be done by CTI, enter the city and state of home nursing service:

City

## D. REFUSAL TO PARTICIPATE

1. Check here to indicate participant refusal. (1)

State

- 2. Reason(s) for proband non-participation YES NO a) Proband not interested (1) (2)b) Proband is too ill (1) (2)c) Proband is fearful of genetics research (1) (3)d) Proband won't complete urine screen (1) (2)e) No reason given (1) (2)f) Other (1) (2)1. Specify: 3. Reason(s) for parents' non-participation NO YES
  - a) Proband does not want parents contacted (1) (2)

Family ID: Proband/Relative	Code:	
	NO	YES
b) Relative estranged from family	(1)	(2)
c) Relative is elderly	(1)	(2)
d) Relative is too ill to participate	(1)	(2)
e) Relative is not interested	(1)	(2)
f) Relative is fearful of exam results	(1)	(2)
g) Relative is fearful of genetics research	(1)	(2)
h) No reason given	(1)	(2)
i) Other	(1)	(2)
1. Specify:		

Name of person completing form:

Certification Number:

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