## GENERAL INSTRUCTIONS

All patients enrolled in the PALF Cohort study are eligible for participation in the genetics study.

The Genetics Consent (GC) form should be completed for all patients who are enrolled in the PALF Cohort study, regardless of whether or not they provide consent for the genetic component of the study. If patients refuse to participate in the genetic component of the PALF Cohort study, they should still be enrolled in the Cohort study.

## SPECIFIC INSTRUCTIONS

**Patient ID:** Record the Patient ID

**Consent:** Record whether or not the patient or parent/guardian has provided consent for participation in the genetics study.

If "Yes", record the following:

- Date the patient or parent/guardian was initially approached for participation in the genetics study (i.e., when the genetic component of the study was explained to the patient or parent/guardian or the consent document was initially offered to the patient or parent/guardian).
- Date the patient or parent/guardian provided consent for the genetics study (i.e., signed the consent documents).

If "No", record the reason consent was not obtained or check "Unknown" if a reason was not provided. If the reason that consent was not obtained is not listed, record 'Other' and specify the reason.