



Medical Record Abstraction Form

Subject ID Label

If date or age is not available, enter '99'.

Visit: 12 Weeks 24 Weeks 36 Weeks

Name of Abstractor: _____

1. Date of Abstraction: |__|__|_|-|__|__|_|-|__|__|__|__|

2. -----QUESTION 2 ANSWERED ONLY AT BASELINE-----

Basic Measurements (most recent)	Not in record	Measurements	Date (mm/dd/yyyy)	Steady state?
3. Height	<input type="checkbox"/>	__ __ __ CM		<input type="checkbox"/> Yes <input type="checkbox"/> No
4. Weight	<input type="checkbox"/>	__ __ __ . __ Kg		<input type="checkbox"/> Yes <input type="checkbox"/> No
5. Temperature	<input type="checkbox"/>	__ __ . __ Celsius		<input type="checkbox"/> Yes <input type="checkbox"/> No
6. Heart Rate	<input type="checkbox"/>	__ __ __ Beats/Minute		<input type="checkbox"/> Yes <input type="checkbox"/> No
7. Respiration Rate	<input type="checkbox"/>	__ __ __ Breaths/Minute		<input type="checkbox"/> Yes <input type="checkbox"/> No
8. Oxygen Saturation (SpO ₂)	<input type="checkbox"/>	__ __ __ %		<input type="checkbox"/> Yes <input type="checkbox"/> No
9. Blood Pressure	<input type="checkbox"/>	__ __ __ / __ __ __ ON ANTI-HYPERTENSIVE MEDS? <input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Yes <input type="checkbox"/> No

10. Hydroxyurea history

a. QUESTION 10A ANSWERED ONLY AT BASELINE

b. MTD dose (select units) _____ Mg/kg Mg/day Mg/kg/day

c. Current dose _____ Mg/kg/day OR _____ Mg/day

d. Was dose held since last visit? Yes No

If no, please select reason: Neutropenia

Reticulocytopenia

Thrombocytopenia

Has the subject ever used these medications →	11. Endari (L-glutamine)? <input type="checkbox"/> Yes <input type="checkbox"/> No → GO TO Q12	12. ADAKVEO (crizanlizumab)? <input type="checkbox"/> Yes <input type="checkbox"/> No → GO TO Q13	13. Oxbryta (voxelotor)? <input type="checkbox"/> Yes <input type="checkbox"/> No → GO TO Q14
a. Start date (mm/yyyy)	_ _ - _ _ _ _	_ _ - _ _ _ _	_ _ - _ _ _ _
b. Stop/last date (mm/yyyy)	_ _ - _ _ _ _ <input type="checkbox"/> Currently using	_ _ - _ _ _ _ <input type="checkbox"/> Currently using	_ _ - _ _ _ _ <input type="checkbox"/> Currently using
c. Total duration of use	____ <input type="checkbox"/> Months <input type="checkbox"/> Years <input type="checkbox"/> Unknown	____ <input type="checkbox"/> Months <input type="checkbox"/> Years <input type="checkbox"/> Unknown	____ <input type="checkbox"/> Months <input type="checkbox"/> Years <input type="checkbox"/> Unknown
d. Current dose	____ g	____ g	____ g
e. Current frequency	<input type="checkbox"/> Twice a day <input type="checkbox"/> Other	<input type="checkbox"/> Once a month <input type="checkbox"/> Other	<input type="checkbox"/> Once a day <input type="checkbox"/> Other

14. Has the subject had any acute care/infusion center visits (not admitted) since last visit?

- Yes
- No acute care visits since last visit → **SKIP TO QUESTION 15**
- Not in record → **SKIP TO QUESTION 15**

Acute Care/Infusion Center Visit (not admitted)	Visit/Admission Date (mm/dd/yyyy)	Was visit for acute pain?	Led to an admission?
Acute Pain/Infusion Center Visit 1		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Acute Pain/Infusion Center Visit 2		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Acute Pain/Infusion Center Visit 3		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Acute Pain/Infusion Center Visit 4		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Acute Pain/Infusion Center Visit 5		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Acute Pain/Infusion Center Visit 6		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Acute Pain/Infusion Center Visit 7		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Acute Pain/Infusion Center Visit 8		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Acute Pain/Infusion Center Visit 9		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Acute Pain/Infusion Center Visit 10		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

15. Has the subject had any emergency department visits (not admitted) since last visit?

- Yes
- No emergency department visits since last visit → **SKIP TO QUESTION 16**
- Not in record → **SKIP TO QUESTION 16**

Emergency Department Visit (not admitted)	Visit/Admission Date (mm/dd/yyyy)	Was visit for acute pain?	Led to an admission?
Emergency Department Visit 1		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Emergency Department Visit 2		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Emergency Department Visit 3		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Emergency Department Visit 4		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Emergency Department Visit 5		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Emergency Department Visit 6		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

16. Has the subject had any hospitalizations since last visit?

- Yes
 No hospitalizations since last visit → **SKIP TO MEDICATIONS TABLE**
 Not in record → **SKIP TO MEDICATIONS TABLE**

Hospitalizations	Visit/Admission Date (mm/dd/yyyy)	Discharge Date (mm/dd/yyyy)	Was visit for acute pain?
First Hospitalization			<input type="checkbox"/> Yes <input type="checkbox"/> No
Second Hospitalization			<input type="checkbox"/> Yes <input type="checkbox"/> No
Third Hospitalization			<input type="checkbox"/> Yes <input type="checkbox"/> No
Fourth Hospitalization			<input type="checkbox"/> Yes <input type="checkbox"/> No
Fifth Hospitalization			<input type="checkbox"/> Yes <input type="checkbox"/> No
Sixth Hospitalization			<input type="checkbox"/> Yes <input type="checkbox"/> No

17. Please list all medications the subject is **currently** taking.

- None currently being used → **SKIP TO TRANSFUSION HISTORY**

Name of Medication	Name of Medication
a.	k.
b.	l.
c.	m.
d.	n.
e.	o.
f.	p.
g.	q.

Name of Medication	Name of Medication
h.	r.
i.	s.
j.	t.

18. Please list transfusion dates.

Transfusion History at Clinic Site								
	None	# ever had	# total units	First time (mm/yyyy)	Last time (mm/yyyy)	Reason stopped	Frequency	Type
Episodic, simple	<input type="checkbox"/>						<input type="checkbox"/> Less than once/year <input type="checkbox"/> About once a year <input type="checkbox"/> More than once/year <input type="checkbox"/> Unknown	
Chronic, simple	<input type="checkbox"/>					<input type="checkbox"/> Hemochromatosis <input type="checkbox"/> Alloimmunization <input type="checkbox"/> Other <input type="checkbox"/> Unknown	<input type="checkbox"/> Once every 4 weeks <input type="checkbox"/> Once every 6 weeks <input type="checkbox"/> Once every 8 weeks <input type="checkbox"/> Unknown	
Episodic, exchange	<input type="checkbox"/>						<input type="checkbox"/> Less than once/year <input type="checkbox"/> About once a year <input type="checkbox"/> More than once/year <input type="checkbox"/> Unknown	<input type="checkbox"/> Automated <input type="checkbox"/> Manual <input type="checkbox"/> Unknown
Chronic, exchange	<input type="checkbox"/>					<input type="checkbox"/> Hemochromatosis <input type="checkbox"/> Alloimmunization <input type="checkbox"/> Other <input type="checkbox"/> Unknown	<input type="checkbox"/> Once every 4 weeks <input type="checkbox"/> Once every 6 weeks <input type="checkbox"/> Once every 8 weeks <input type="checkbox"/> Unknown	<input type="checkbox"/> Automated <input type="checkbox"/> Manual <input type="checkbox"/> Unknown

19. Hydroxyurea Prescription Refills Patient did not fill any hydroxyurea prescriptions since last visit → **SKIP TO END**

For each refill, complete a row in the table:

Refill	19. Pharmacy Contact Information		20. Date prescription picked up (mm/dd/yyyy)	21. Number of days' Supply	22. Name of prescribing provider
	19. Name of pharmacy	19a-e: Address and phone number of pharmacy			
Hydroxyurea Refill 1					
Hydroxyurea Refill 2					
Hydroxyurea Refill 3					
Hydroxyurea Refill 4					
Hydroxyurea Refill 5					
Hydroxyurea Refill 6					
Hydroxyurea Refill 7					
Hydroxyurea Refill 8					
Hydroxyurea Refill 9					
Hydroxyurea Refill 10					
Hydroxyurea Refill 11					
Hydroxyurea Refill 12					
Hydroxyurea Refill 13					

Refill	19. Pharmacy Contact Information		20. Date prescription picked up (mm/dd/yyyy)	21. Number of days' Supply	22. Name of prescribing provider
	19. Name of pharmacy	19a-e: Address and phone number of pharmacy			
Hydroxyurea Refill 14					
Hydroxyurea Refill 15					
Hydroxyurea Refill 16					
Hydroxyurea Refill 17					
Hydroxyurea Refill 18					
Hydroxyurea 19					
Hydroxyurea 20					

These are all the hydroxyurea refills available in the record since the previous study visit.

- Yes
- No

PI review and sign-off: _____