

This form should be completed using data abstracted from the medical record. This should be completed going back to the **date the last abstraction form was completed**.

DATE THIS FORM COMPLETED: |__|_|_|-|__|_|_|-|__|_|_|_|_|_|

DATE LAST ABSTRACTION FORM COMPLETED: |__|_|_|-|__|_|_|-|__|_|_|_|_|_|

DATE PATIENT LAST KNOWN TO BE ALIVE: |__|_|_|-|__|_|_|-|__|_|_|_|_|_|

MEDICAL RECORDS NOT AVAILABLE, FORM COMPLETE

1. Has the subject received a bone marrow transplant (BMT) since the date of the last abstraction?
 - Yes → Date of BMT: |__|_|-|__|_|-|__|_|_|_|_| (report data only up to BMT date. Complete Off-Study Form.)
 - No
2. Has the subject been evaluated for curative gene therapy since the date of the last abstraction? Yes No
3. Test results for alpha-thalassemia since the date of last abstraction?
 - Yes—single alpha globin gene deleted
 - Yes—two alpha globin genes deleted
 - Yes—negative
 - No—not evaluated
 - Unknown

Basic Measurements (most recent)	Not in Record	Measurements	Date (mm/yyyy)	Steady state?
4. Height	<input type="checkbox"/>	__ _ _ _ CM		Y N
5. Weight	<input type="checkbox"/>	__ _ _ _ . _ _ KG		Y N
6. Temperature	<input type="checkbox"/>	__ _ _ . _ _ Celsius		Y N
7. Heart Rate	<input type="checkbox"/>	__ _ _ _ BEATS/MINUTE		Y N
8. Respiration Rate	<input type="checkbox"/>	__ _ _ _ BREATHS/MINUTE		Y N
9. Oxygen saturation (SpO ₂)	<input type="checkbox"/>	__ _ _ _ %		Y N
10. Blood Pressure	<input type="checkbox"/>	__ _ _ _ / __ _ _ _ ON ANTI-HYPERTENSIVE MEDS? <input type="checkbox"/> Yes <input type="checkbox"/> No		Y N

12. Is the subject currently taking hydroxyurea? Yes No
13. Has the subject started or stopped hydroxyurea since the date of last abstraction? Yes No → **GO TO Q14**
 - a. Start date (mm/yyyy) |__|_|-|__|_|_|_|_|
 - b. Stop/last date (mm/yyyy) |__|_|-|__|_|_|_|_| Currently using
 - c. Total duration of use ____ Months or Years Unknown
 - d. Current dose ____ Mg/kg or _ Mg

14. Is the subject currently taking Endari? Yes No

15. Has the subject started or stopped Endari since the date of last abstraction? Yes No → GO TO Q16

- a. Start date (mm/yyyy) |__|__|-|__|__|__|__|
- b. Stop/last date (mm/yyyy) |__|__|-|__|__|__|__| Currently using
- c. Total duration of use ____ Months or Years Unknown
- d. Current dose ____ Mg/kg or _ Mg

16. Is the subject currently taking Adakveo? Yes No

17. Has the subject started or stopped Adakveo since the date of last abstraction? Yes No → GO TO Q18

- a. Start date (mm/yyyy) |__|__|-|__|__|__|__|
- b. Stop/last date (mm/yyyy) |__|__|-|__|__|__|__| Currently using
- c. Total duration of use ____ Months or Years Unknown
- d. Current dose ____ _ Mg/kg or __ Mg

18. Is the subject currently taking Oxbryta? Yes No

19. Has the subject started or stopped Oxbryta since the date of last abstraction? Yes No → GO TO Q20

- a. Start date (mm/yyyy) |__|__|-|__|__|__|__|
- b. Stop/last date (mm/yyyy) |__|__|-|__|__|__|__| Currently using
- c. Total duration of use ____ Months or Years Unknown
- d. Current dose ____ Mg/kg or _ Mg

20. Please list all medications the subject is **currently** taking. NONE CURRENTLY BEING USED

Name of Medication	Name of Medication
a.	k.
b.	l.
c.	m.
d.	n.
e.	o.
f.	p.
g.	q.
h.	r.
i.	s.
j.	t.

SCD Complications since the last abstraction			
<u>Ever present in timeframe</u> : previously reported condition still being actively monitored or treated or a new diagnosis within the timeframe of abstraction <u>Date of new diagnosis</u> : chronic condition not previously diagnosed or a most recent episode of an acute condition within the timeframe of abstraction <u>Received treatment</u> : received an intervention within the timeframe of abstraction (i.e. surgery, procedure, medication)	Ever present in timeframe	Date of new diagnosis only (mm/yyyy)	Received treatment in timeframe
Musculoskeletal			
24. Avascular necrosis (<i>check all that apply</i>)	<input type="checkbox"/>		<input type="checkbox"/>
a. Hip	<input type="checkbox"/>		<input type="checkbox"/>
b. Shoulder	<input type="checkbox"/>		<input type="checkbox"/>
c. Knee	<input type="checkbox"/>		<input type="checkbox"/>
d. Other location, specify _____	<input type="checkbox"/>		<input type="checkbox"/>
Genitourinary			
25. Chronic kidney disease	<input type="checkbox"/>		<input type="checkbox"/>
26. End stage renal disease (<i>if yes, complete Renal form</i>)	<input type="checkbox"/>		<input type="checkbox"/>
a. Kidney transplant	<input type="checkbox"/>		
b. Kidney transplant rejection	<input type="checkbox"/>		
27. Priapism	<input type="checkbox"/>		<input type="checkbox"/>
Nervous system			
28. Stroke (<i>check all that apply</i>)	<input type="checkbox"/>		<input type="checkbox"/>
a. Ischemic	<input type="checkbox"/>		<input type="checkbox"/>
b. Hemorrhagic	<input type="checkbox"/>		<input type="checkbox"/>
c. Transient ischemic attack (TIA)	<input type="checkbox"/>		<input type="checkbox"/>
d. Silent	<input type="checkbox"/>		<input type="checkbox"/>
29. Intracranial bleeding	<input type="checkbox"/>		<input type="checkbox"/>
Cardiovascular			
30. Pulmonary arterial hypertension	<input type="checkbox"/>		<input type="checkbox"/>
a. Mean pulmonary artery pressure > or = to 25 mm Hg	<input type="checkbox"/>		<input type="checkbox"/>
b. Tricuspid regurgitation velocity (TRV) > or = to 3.0 m/sec	<input type="checkbox"/>		<input type="checkbox"/>
31. Left ventricular dysfunction	<input type="checkbox"/>		<input type="checkbox"/>
Respiratory			
32. Acute chest syndrome	<input type="checkbox"/>		<input type="checkbox"/>
33. Asthma	<input type="checkbox"/>		<input type="checkbox"/>
Digestive			
34. Gallstones/cholelithiasis, cholecystitis	<input type="checkbox"/>		<input type="checkbox"/>
35. Splenomegaly (<i>check all that apply</i>)	<input type="checkbox"/>		<input type="checkbox"/>
a. PRBC transfusion given for splenomegaly? <input type="checkbox"/> Yes <input type="checkbox"/> No			
b. Splenic sequestration	<input type="checkbox"/>		<input type="checkbox"/>
# sequestration episodes in past 12 months _____			
c. Splenic infarcts, symptomatic	<input type="checkbox"/>		<input type="checkbox"/>
d. Hypersplenism	<input type="checkbox"/>		<input type="checkbox"/>
e. Splenectomy	<input type="checkbox"/>		
Other Autoimmune/Inflammatory			
36. Deep vein thrombosis (DVT)	<input type="checkbox"/>		<input type="checkbox"/>
a. Pulmonary embolism	<input type="checkbox"/>		<input type="checkbox"/>
b. Venous thromboembolism (VTE)	<input type="checkbox"/>		<input type="checkbox"/>
37. Lupus	<input type="checkbox"/>		<input type="checkbox"/>
38. Rheumatoid arthritis	<input type="checkbox"/>		<input type="checkbox"/>

SCD Complications since the last abstraction			
<u>Ever present in timeframe</u> : previously reported condition still being actively monitored or treated or a new diagnosis within the timeframe of abstraction			
<u>Date of new diagnosis</u> : chronic condition not previously diagnosed or a most recent episode of an acute condition within the timeframe of abstraction			
<u>Received treatment</u> : received an intervention within the timeframe of abstraction (i.e. surgery, procedure, medication)			
	Ever present in timeframe	Date of new diagnosis only (mm/yyyy)	Received treatment in timeframe
39. Gout	<input type="checkbox"/>		<input type="checkbox"/>
40. Sarcoidosis	<input type="checkbox"/>		<input type="checkbox"/>
Other Conditions			
41. Multi-organ failure (<i>check all that apply</i>)	<input type="checkbox"/>		
a. ICU			<input type="checkbox"/>
b. Intubation			<input type="checkbox"/>
c. Simple transfusion			<input type="checkbox"/>
d. Exchange transfusion			<input type="checkbox"/>
e. Hemodialysis			<input type="checkbox"/>
f. Peritoneal dialysis			<input type="checkbox"/>
42. Pneumococcal sepsis	<input type="checkbox"/>		<input type="checkbox"/>
43. Skin ulcers	<input type="checkbox"/>		<input type="checkbox"/>
44. Retinopathy	<input type="checkbox"/>		<input type="checkbox"/>
45. Diabetes mellitus	<input type="checkbox"/>		<input type="checkbox"/>
46. Iron overload (liver iron content > 3 mg/g of dry weight liver on MRI or serum ferritin above 1,000 ng/dL for >3 separate measurements or >18 PRBCs)	<input type="checkbox"/>		<input type="checkbox"/>
47. Chronic refractory pain	<input type="checkbox"/>		<input type="checkbox"/>
48. Seizure disorder	<input type="checkbox"/>		<input type="checkbox"/>
49. Anxiety	<input type="checkbox"/>		<input type="checkbox"/>
50. Depression	<input type="checkbox"/>		<input type="checkbox"/>
51. Other psychiatric disorder, specify:	<input type="checkbox"/>		<input type="checkbox"/>
52. Other major health condition, specify:	<input type="checkbox"/>		<input type="checkbox"/>
Liver Conditions			
53. Liver cirrhosis	<input type="checkbox"/>		<input type="checkbox"/>
54. Intrahepatic cholelithiasis	<input type="checkbox"/>		<input type="checkbox"/>
55. Hepatitis B	<input type="checkbox"/>		<input type="checkbox"/>
56. Hepatitis C	<input type="checkbox"/>		<input type="checkbox"/>
57. Hepatic sequestration	<input type="checkbox"/>		<input type="checkbox"/>
58. Hepatomegaly	<input type="checkbox"/>		<input type="checkbox"/>
59. Bridging fibrosis	<input type="checkbox"/>		<input type="checkbox"/>

60. Has the subject been diagnosed with a primary cancer since the last abstraction?

- Yes
- No → GO TO Q61
- Don't know → GO TO Q61

a. CANCER TYPE AND LOCATION _____

b. CANCER STAGE _____

c. DATE OF DIAGNOSIS (MM/YYYY): |__|_|_| |__|_|_|_|_|_|

61. What kind of health insurance or health care coverage does the subject currently have? (Choose all that apply.)

- None
- Private health insurance
- Medicare
- Medicaid, Medical Assistance (MA), the Children's Health Insurance Program (CHIP), or any kind of state or government-sponsored assistance
- TRICARE or other military health care, including VA health care
- Support from Charities or Donations
- Other type of health insurance, specify: _____

Name of Abstractor: _____

PI review and sign-off: _____