

Follow-up Medical Record Abstraction Form - v1.0

Subject ID

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**.

P.					
DATE THIS FORM COMPLETI	ED: _	_ -			
DATE LAST ABSTRACTION F	FORM COMI	PLETED:	_		
	IN TO DE A	INT.	ı		
DATE PATIENT LAST KNOW	VN TO BE A	LIVE: - - -			
☐ MEDICAL RECO	RDS NOT	T AVAILABLE, FORM COMPLETE			
1 Use the subject received	o hono mor	row transplant (BMT) since the date of the last	abstraction?		
•		_ - _ - _ _ (report data only			
	c or bivir.	Complete Off-Stu	•		
\square No					
2. Has the subject been eval	luated for c	urative gene therapy since the date of the last al			
3 Test results for alpha-tha	lassemia sii	nce the date of last abstraction?	\square No		
•		n gene deleted			
☐ Yes—two al					
☐ Yes—negati					
□ No—not eva□ Unknown	luated				
□ Ulikilowii					
Basic Measurements	Not in		D . 4 :	1	
			Date		
(most recent)	Record	Measurements	Date (mm/yyyy)	Steady	state?
(most recent) 4. Height	Record	Measurements		Steady Y	state?
`				•	
4. Height		_ CM		Y	N
4. Height 5. Weight		_ CM _ . KG		Y	N N
4. Height5. Weight6. Temperature		CM . KG _ . Celsius		Y Y Y	N N N
4. Height5. Weight6. Temperature7. Heart Rate		CM _ . KG . _ . _ Celsius _ BEATS/MINUTE		Y Y Y Y	N N N
 4. Height 5. Weight 6. Temperature 7. Heart Rate 8. Respiration Rate 		_ CM _ KG . _ Celsius BEATS/MINUTE _ BREATHS/MINUTE		Y Y Y Y Y Y Y	N N N N N
 Height Weight Temperature Heart Rate Respiration Rate Oxygen saturation (SpO₂) 		_ CM _ KG . _ Celsius BEATS/MINUTE _ BREATHS/MINUTE		Y Y Y Y Y Y	N N N N
 Height Weight Temperature Heart Rate Respiration Rate Oxygen saturation (SpO₂) 		_ CM _ KG . _ Celsius BEATS/MINUTE _ BREATHS/MINUTE _ %		Y Y Y Y Y Y Y	N N N N N
 Height Weight Temperature Heart Rate Respiration Rate Oxygen saturation (SpO₂) 		CM _ KG _ Celsius _ BEATS/MINUTE _ BREATHS/MINUTE _ % / _ W		Y Y Y Y Y Y Y	N N N N N
4. Height 5. Weight 6. Temperature 7. Heart Rate 8. Respiration Rate 9. Oxygen saturation (SpO ₂) 10. Blood Pressure	cking hydro	CM _ KG _ Celsius _ BEATS/MINUTE _ BREATHS/MINUTE _ % / _ W	(mm/yyyy)	Y Y Y Y Y Y Y Y	N N N N N
4. Height 5. Weight 6. Temperature 7. Heart Rate 8. Respiration Rate 9. Oxygen saturation (SpO ₂) 10. Blood Pressure	aking hydro	_ CM _ KG _ Celsius BEATS/MINUTE _ BREATHS/MINUTE _ W	(mm/yyyy)	Y Y Y Y Y Y Y Y	N N N N N
4. Height 5. Weight 6. Temperature 7. Heart Rate 8. Respiration Rate 9. Oxygen saturation (SpO ₂) 10. Blood Pressure 12. Is the subject currently ta 13. Has the subject started or	aking hydro	_ CM _ KG _ KG _ Eats/MINUTE _ _ BEATS/MINUTE _ _ BREATHS/MINUTE _ W ON ANTI-HYPERTENSIVE MEDS?	(mm/yyyy) □ Yes □ No → G	Y Y Y Y Y Y Y Y	N N N N N
4. Height 5. Weight 6. Temperature 7. Heart Rate 8. Respiration Rate 9. Oxygen saturation (SpO ₂) 10. Blood Pressure 12. Is the subject currently ta 13. Has the subject started or a. Start date (m	aking hydro	_ CM _ KG _ Celsius BEATS/MINUTE _ BREATHS/MINUTE _ W ON ANTI-HYPERTENSIVE MEDS?	(mm/yyyy) □ Yes □ No → G	Y Y Y Y Y Y Y Y	N N N N N

_ Mg/kg or _ Mg

d. Current dose

14. Is the subje	ect currently taking Endari? Yes No	
15. Has the sub	oject started or stopped Endari since the date of	Flast 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 o	r
d.	Current dose Mg/kg or _	Mg
16. Is the subje	ect currently taking Adakveo? Yes N	0
17. Has the sub	oject 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	or
d.	Current dose Mg/kg	or Mg
· ·	ect currently taking Oxbryta? Yes No	
19. Has the sub	pject 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	r
d.	Current dose Mg/kg or _	Mg
20. Please list a	all medications the subject is currently taking.	\square None currently being used
Name of Me	dication	Name of Medication
a.		k.
b.		1.
d.		n.
e.		0.
f.		p.
g.		q.
h.		r.
i.		s.
j.		t.

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

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

60. Has the su	ubject been diagnosed with a primary cancer since the last abstraction?
	es o → Go To Q61 on't know → Go To Q61
a.	. CANCER TYPE AND LOCATION
b	. CANCER STAGE
c.	. DATE OF DIAGNOSIS (MM/YYY):
61. What kind	d of health insurance or health care coverage does the subject currently have? (Choose all that apply.)
\square No	one
□ Pri	ivate health insurance
\square Mo	edicare
	edicaid, Medical Assistance (MA), the Children's Health Insurance Program (CHIP), or any kind of state or vernment-sponsored assistance
	RICARE or other military health care, including VA health care
□ Su	pport from Charities or Donations
□ Ot	her type of health insurance, specify:
Name of Abstra	actor: PI review and sign-off: