

Abstraction from Medical Chart Enrollment – Patient Characteristics

Study ID	Study_id	Initials	
CIBMTR Universal ID	cibmtr_id	Consent Date	consent_dt
Enrollment date	enroll_dt	Study Site	
Case Type <input type="checkbox"/> Incident <input type="checkbox"/> Prevalent <p style="margin-left: 100px;"><i>p-case</i></p>		<input type="checkbox"/> Fred Hutchinson Cancer Research Center <input type="checkbox"/> University of Minnesota <input type="checkbox"/> Dana-Farber Cancer Institute <input type="checkbox"/> Stanford University <input type="checkbox"/> Vanderbilt University <input type="checkbox"/> H. Lee Moffitt Cancer Center <input type="checkbox"/> Roswell Park Cancer Institute <input type="checkbox"/> Cleveland Clinic <input type="checkbox"/> Ohio State University <input type="checkbox"/> University of British Columbia <input type="checkbox"/> Duke University <input type="checkbox"/> MD Anderson <p style="margin-left: 100px;"><i>site</i></p>	
Age Group	<input type="checkbox"/> Adult (18+) <input type="checkbox"/> Ped (2-17) <p style="margin-left: 100px;"><i>adult-child</i></p>	Patient age at enrollment	age_enroll
Patient Gender	<input type="checkbox"/> Male <input type="checkbox"/> Female <p style="margin-left: 100px;"><i>gender</i></p>	Patient Race	<input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Black or African-American <input type="checkbox"/> Native Hawaiian or Other Pacific Islander <input type="checkbox"/> White <input type="checkbox"/> Multi-race <input type="checkbox"/> Unknown <input type="checkbox"/> Other <p style="margin-left: 100px;"><i>race</i></p> <p style="margin-left: 100px;"><i>race-other</i></p>
Ethnicity	<input type="checkbox"/> Hispanic descent <input type="checkbox"/> Not Hispanic descent <p style="margin-left: 100px;"><i>ethnicity</i></p>		

Abstraction from Medical Chart Baseline Data – Transplant Characteristics

Study ID	study_id	Initials		Date of Transplant	tx_dt
Height pre-tx	ht_pre	Weight pre-tx	wt_pre		
PFT pre-tx <small>(use post BD values if available)</small>	<input type="checkbox"/> Yes, without bronchodilator <input type="checkbox"/> Yes, with bronchodilator <input type="checkbox"/> No		PFT pre-tx Date	pft_pre_dt	
FVC	fvc - L_pre	L	fvc_pre	% predicted	
FEV-1	fev1 - L_pre	L	fev1_pre	% predicted	
TLC	tlc_pre	L	RV	rv_pre	L
Single breath DLCO (adjusted for hemoglobin)			dico_pre	% predicted	
Patient Age at Tx	age_trans	Age of Donor	dnr_age		
Disease Status	dis_dx	Early dis-status	Intermed.	Adv.	
1 AML	<input type="checkbox"/> CR1 1	<input type="checkbox"/> CR2 6	<input type="checkbox"/> CR3+, rel, ref, IF 13		
2 ALL	<input type="checkbox"/> CR1 1	<input type="checkbox"/> CR2 6	<input type="checkbox"/> CR3+, rel, ref, IF 13		
3 CML	<input type="checkbox"/> CP 2	<input type="checkbox"/> AP 7	<input type="checkbox"/> BC or after BC 14		
4 CLL		<input type="checkbox"/> CR, PR, CS 8	<input type="checkbox"/> Rel, ref, CI 15		
5 MDS	<input type="checkbox"/> RA, RARS 3	<input type="checkbox"/> RAEB, RAEBT 9	<input type="checkbox"/> Rel, ref, IF 16		
6 NHL		<input type="checkbox"/> CR, PR, CS 8	<input type="checkbox"/> Rel, ref, CI 15		
7 HD		<input type="checkbox"/> CR, PR, CS 8	<input type="checkbox"/> Rel, ref, CI 15		
8 MPD		<input type="checkbox"/> CR, PR, CS, no chemo 10	<input type="checkbox"/> Rel, ref, CI 15		
9 MM		<input type="checkbox"/> CR, PR, CS 8	<input type="checkbox"/> Rel, ref, CI 15		
10 AA	<input type="checkbox"/> Without ATG/TG 4	<input type="checkbox"/> With ATG/TG 11			
Other, spec:	99	<input type="checkbox"/> Early (non-maliq) 5	<input type="checkbox"/> Intermed. (CR, PR) 12	<input type="checkbox"/> Adv. (Rel, ref, CI) 17	
Transplant Source	<input type="checkbox"/> Peripheral Blood 1 <input type="checkbox"/> Bone Marrow 2 <input type="checkbox"/> Cord Blood 3	CMV antibodies? 1	Patient: <input type="checkbox"/> Positive/equivocal pt_cmv <input type="checkbox"/> Negative		
Transplant Type	<input type="checkbox"/> Myeloablative 1 <input type="checkbox"/> Reduced intensity 2 <input type="checkbox"/> Non-myeloablative 3	0	Donor: <input type="checkbox"/> Positive/equivocal dnr_cmv <input type="checkbox"/> Negative		
Donor Gender <small>(choose 2 genders if double cord)</small>	<input type="checkbox"/> Male 0 <input type="checkbox"/> Female 1 <input type="checkbox"/> Female/Female 2 <input type="checkbox"/> Male/Male 3 <input type="checkbox"/> Male/Female 4	Donor Match	<input type="checkbox"/> HLA-identical sibling <input type="checkbox"/> HLA-matched other relative <input type="checkbox"/> HLA-mismatched relative (1 antigen mismatched) <input type="checkbox"/> Haploidentical relative (≥ 2 mismatched) <input type="checkbox"/> Matched Unrelated Donor <input type="checkbox"/> Mismatched Unrelated Donor		
Preparative Regimen	GVHD prophylaxis				
prep_rx (text)	prep_rx_cd (code)		prophyl (text)		
prep_rx_oth	prep_mod 1-3		p-med 1-5 (code)		
			p_oth		

Abstraction from Medical Chart Baseline Data – Transplant Characteristics

		T-cell depletion (ex vivo only)				
		<input type="checkbox"/> Yes, specify: _____ <input type="checkbox"/> No <div style="text-align: center;">+tcell-dep +tcell-dep-spec</div>				
Any acute GVHD?	<input type="checkbox"/> Yes <input type="checkbox"/> No agvhd					
Maximum Acute GVHD Grade before day 100						
Overall	agvh-over	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Liver	agvh-lv	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
GI	agvh-gi	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Skin	agvh-skin	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Therapy given for Acute GVHD						
Medications and procedures used to treat Acute GVHD (no dose or date required)						
1.	a-ste-type	6.				
2.	a-med-1-7 (coded)	7.				
3.		8.				
4.		9.				
5.		10.				
Notes	tx char-notes					

Abstraction from Medical Chart Diagnosis Data – Chronic GVHD

Study ID		Initials		Date of chronic GVHD dx	cgvhd-dt
CHARACTERISTICS OF CHRONIC GVHD AT DIAGNOSIS					
Same as study enrollment date? cgvhd-enroll	<input type="checkbox"/> Yes <input type="checkbox"/> No	Weight		<input type="checkbox"/> Kg wt-o <input type="checkbox"/> Lb	
Acute GVHD present the week before chronic GVHD diagnosis?	acute-before-o <input type="checkbox"/> Yes <input type="checkbox"/> No	Type of GVHD at the time of diagnosis?		gvhd-type-o <input type="checkbox"/> Overlap acute and chronic GVHD <input type="checkbox"/> Classic chronic GVHD	
PFTs (list post bronchodilator values below)	<input type="checkbox"/> Yes, without bronchodilator <input type="checkbox"/> Yes, with bronchodilator <input type="checkbox"/> No pft-done-o	Date of PFT (+/- 2 mo from date of cGVHD dx)		pft-o-dt	
FVC	fvc-l-o	L	fvc-o	%	
FEV-1	fev1-1-o	L	fev1-o	%	
TLC	tcl-o	L	RV	<input checked="" type="checkbox"/> rv-o	L
DLCO Single breath (adjusted for hemoglobin)			dlco-o	%	<input type="checkbox"/> Not done
Karnofsky or Lansky Score			kps-o/lps-o	%	<input type="checkbox"/> Not done
Date of Lab Tests	labs-o-dt		<input type="checkbox"/> Not done		
Total WBC	wbc-o k/ul	<input type="checkbox"/> Not done	Platelet count	plt-o k/ul	<input type="checkbox"/> Not done
% Neutrophils	neut-o %	<input type="checkbox"/> Not done	% Lymphocytes	lym-o %	<input type="checkbox"/> Not done
% Eosinophils	eos-o %	<input type="checkbox"/> Not done	AST	ast-o units/L	<input type="checkbox"/> Not done
Total bilirubin	bili-o mg/dL	<input type="checkbox"/> Not done	ALT	alt-o units/L	<input type="checkbox"/> Not done
Albumin	alb-o gm/dL	<input type="checkbox"/> Not done	Alkaline Phosphatase	alk-o units/L	<input type="checkbox"/> Not done

Abstraction from Medical Chart At Study-Related Clinic Visit—Enrollment

Study ID		Initials		Date of clinic visit	
DIAGNOSTIC AND LABORATORY DATA					
Weight	<input type="checkbox"/> Kg <input type="checkbox"/> Lb <i>wt-rpt</i>	Was a research sample drawn?		<input type="checkbox"/> Yes <input type="checkbox"/> No <i>Sample-draw</i>	
PFTs done <i>(enter post BD)</i>	<input type="checkbox"/> Yes, without bronchodilator <input type="checkbox"/> Yes, with bronchodilator <input type="checkbox"/> No <i>pft-done</i>	Date of PFT <i>(+/- 2 mo from visit)</i>		<i>pft_dt</i>	
Full Volume Capacity (FVC)	<i>fvc-1</i>	L	<i>fvc</i>	%	
FEV-1	<i>fev1-1</i>	L	<i>fev1</i>	%	
TLC	<i>tlc</i>	L	RV	<i>rv</i>	L
DLCO Single breath (adjusted for hemoglobin)		<i>dlco</i>	%	<input type="checkbox"/> Not done	
Date of Lab Tests	<i>labs_dt</i>	<input type="checkbox"/> No labs	Total WBC	<i>wbc</i>	k/ul <input type="checkbox"/> Not done
% Neutrophils	<i>neu</i> %	<input type="checkbox"/> Not done	Platelet count	<i>plt</i>	k/ul <input type="checkbox"/> Not done
% Eosinophils	<i>eos</i> %	<input type="checkbox"/> Not done	% Lymphocytes	<i>lym</i>	% <input type="checkbox"/> Not done
Total bilirubin	<i>bili</i> mg/dL	<input type="checkbox"/> Not done	AST	<i>ast</i>	units/L <input type="checkbox"/> Not done
Albumin	<i>alb</i> g/dL	<input type="checkbox"/> Not done	ALT	<i>alt</i>	units/L <input type="checkbox"/> Not done
LDL	<i>ldl</i> mg/dL	<input type="checkbox"/> Not done	ALK phosphatase	<i>alk</i>	units/L <input type="checkbox"/> Not done
Current Medications					
<i>List all medications that the patient is currently taking for chronic GVHD. Include dose regimen of steroids & other GVHD therapy. Do not include new medications or dosage changes prescribed today.</i>					
<i>med-e1 med-dose1 up to 20 meds</i> <i>med-e1-code med-dose2</i> <i>med-e2 etc.</i> <i>med-e2-code</i> <i>etc.</i>					
What is the index medication(s) or treatment(s) for the purposes of the protocol? <i>(What new GVHD therapy was added?)</i>			What date was this therapy started?		Which line of therapy is it?
<i>meds_index_code1-3</i>			<i>meds_index_dt</i>		<i>med_index_ind</i>
WALK TEST					
Total distance walked in 2 minutes:	<input type="checkbox"/> Missing <i>walk-done</i>	Number of laps	x 50 ft= _____	+ Partial lap _____ ft	= _____ Feet walked in 2 min
Patient walked <u>less than</u> 2 minutes?	<input type="checkbox"/> Yes <input type="checkbox"/> No <i>walk-less</i>			<i>walk</i> Feet walked in _____ min <i>walk-time</i>	
Reason why test is missing or not trustworthy:		<i>walk-miss-reas</i>			

Abstraction from Medical Chart At Study-Related Clinic Visit—Follow Up

Study ID		Initials		Date of clinic visit	
Time point	<input type="checkbox"/> 3 month <input type="checkbox"/> 6 month <input type="checkbox"/> 18 month <input type="checkbox"/> Treatment change-abbreviated visit				
DIAGNOSTIC AND LABORATORY DATA					
Weight	<input type="checkbox"/> Kg <input type="checkbox"/> Lb	Was a research sample drawn?		<input type="checkbox"/> Yes <input type="checkbox"/> No	
PFTs done? <i>(enter post BD)</i>	<input type="checkbox"/> Yes, without bronchodilator <input type="checkbox"/> Yes, with bronchodilator <input type="checkbox"/> No	Date of PFT <i>(+/- 2 mo from study visit)</i>			
Full Volume Capacity (FVC)			L		%
FEV-1			L		%
TLC			L	RV	L
DLCO Single breath (adjusted for hemoglobin)				%	<input type="checkbox"/> Not done
Date of Lab Tests		<input type="checkbox"/> No labs	Total WBC	k/ul	<input type="checkbox"/> Not done
% Neutrophils	%	<input type="checkbox"/> Not done	Platelet count	k/ul	<input type="checkbox"/> Not done
% Eosinophils	%	<input type="checkbox"/> Not done	% Lymphocytes	%	<input type="checkbox"/> Not done
Total bilirubin	mg/dL	<input type="checkbox"/> Not done	AST	units/L	<input type="checkbox"/> Not done
Albumin	g/dL	<input type="checkbox"/> Not done	ALT	units/L	<input type="checkbox"/> Not done
LDL	mg/dL	<input type="checkbox"/> Not done	ALK phosphatase	units/L	<input type="checkbox"/> Not done
Since the last study visit: <i>chart_rev_treat_start</i> Any new systemic treatment started for chronic GVHD? <input type="checkbox"/> Yes (report on status form) <input type="checkbox"/> No					
Which med: <i>index 2 - code 1-3</i>					
Since the last study visit: <i>chart_rev_treat_stop</i> All systemic treatment stopped for chronic GVHD? <input type="checkbox"/> Yes (report on status form) <input type="checkbox"/> No					
Current Medications					
<i>List all medications that the patient is currently taking for chronic GVHD. Include dose regimen of steroids & other GVHD therapy. Do not include new medications or dosage changes prescribed today.</i>					

Abstraction from Medical Chart At Study-Related Clinic Visit—Follow Up

The following sections DO NOT need to be completed when treatment change occurs –
abbreviated assessment

Study ID		Initials		Date of clinic visit	
Time point	<input type="checkbox"/> 3 month <input type="checkbox"/> 6 month <input type="checkbox"/> 18 month <input type="checkbox"/> Treatment change-abbreviated visit				

WALK TEST					
Total distance walked in 2 minutes:	<input type="checkbox"/> Missing	Number of laps	x 50 ft= _____	+ Partial lap _____ ft	= _____ Feet walked in 2 min
Patient walked <u>less than</u> 2 minutes?		<input type="checkbox"/> Yes <input type="checkbox"/> No		_____ Feet walked in _____ min	
Reason why test is missing or not trustworthy:					

If your center will allow pathology review for study patients: Number of biopsy samples taken during <i>interval between</i> study visits?				<i>bx-number</i>
Area of body:	Date of biopsy:	Location: <i>bx1-loc</i>		Pathology reference number & Diagnosis/Results:
<i>bx1-area</i>	<i>bx1-dt</i>	<input type="checkbox"/> At center 1	<input type="checkbox"/> Outside center 2	<i>bx1-path</i>
<i>bx2-area</i>	<i>bx2-dt</i>	<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
<i>etc.</i>		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
<i>upto 10</i>		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	

Abstraction from Medical Chart At Endpoint

Study ID		Date of endpoint		<input type="checkbox"/> Relapse <input type="checkbox"/> Death
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If your center will allow pathology review for study patients: Number of biopsy samples taken during <i>interval between</i> study visits?				<i>end-bx-number</i>
Area of body:	Date of biopsy:	Location: <i>end-bx1-loc</i>		Pathology reference number & Diagnosis/Results:
<i>end-bx1-area</i>	<i>end-bx1-dt</i>	<input type="checkbox"/> At center 1	<input type="checkbox"/> Outside center 2	<i>end-bx1-path</i>
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	
		<input type="checkbox"/> At center	<input type="checkbox"/> Outside center	

atendpt - bx, meds from last visit to rel/dth

Comorbidities in cGVHD Scale
(Adapted from Sorrow Scale)

Study ID	Initials	Date of clinic visit		
Time point	<input type="checkbox"/> Enrollment	<input type="checkbox"/> 6 month	<input type="checkbox"/> 18 month	<input type="checkbox"/> Treatment Change <i>cmb visit type</i>
Comorbidity	Definition		Present (circle)	
1. CARDIOVASCULAR	<i>cmb - cardio</i>			
Arrhythmia 0	Atrial fibrillation or flutter, sick sinus syndrome or ventricular arrhythmias in past/present requiring treatment		A	
Cardiac 1	Coronary artery disease, congestive heart failure responding to treatment, or myocardial infarction in past/present, or EF \leq 50% on most recent test		B	
Heart valve disease 2	Moderate or severe valve stenosis or insufficiency as determined by echo, prosthetic valve, symptomatic mitral valve prolapse		C	
Cerebrovascular disease 3	Transient ischemic attack or history of cerebrovascular accident (subarachnoid hemorrhage, cerebral thrombosis, embolism or hemorrhage) regardless of treatment		D	
2. GASTROINTESTINAL	<i>cmb - gi</i>			
Peptic ulcer 0	Gastric or duodenal ulcer documented by endoscopy or radiography in past/present regardless of treatment		E	
Mild hepatic 1	Documented hepatitis B or C in past/present, bilirubin $>$ ULN to 1.5 x ULN, or AST/ALT $>$ ULN to 2.5 x ULN documented on two tests. Use the most recent test to determine severity.		F	
Moderate/severe hepatic 2	Liver cirrhosis in past/present, bilirubin $>$ 1.5 times ULN or AST/ALT $>$ 2.5 x ULN documented on two tests. Use the most recent test to determine severity.		G	
Inflammatory bowel disease 3	Crohn's disease or ulcerative colitis in past/present requiring treatment		H	
3. PULMONARY	<i>cmb - pulm</i>			
Moderate pulmonary 0	DLCOcorr and/or FEV-1 66%-80% or dyspnea with slight activity that is attributed to pulmonary disease within the past 2 weeks		I	
Severe pulmonary 1	DLCOcorr and/or FEV-1 65% or lower, or dyspnea at rest that is attributed to pulmonary disease or need for intermittent or continuous oxygen within the past 4 weeks		J	
4. ENDOCRINE	<i>cmb - endo</i>			
Diabetes 0	Requiring treatment with insulin or oral hypoglycemic agents but not diet alone in the past 4 weeks		K	
5. NEUROPSYCHIATRIC	<i>cmb - neuro</i>			
Psychiatric disturbance 0	Depression, anxiety or other mental disorders requiring continuous treatment during the past 4 weeks. As needed medications do not count.		L	
6. RHEUMATOLOGIC	<i>cmb - rheuma</i>			
Rheumatologic 0	Lupus, Sjogren's syndrome, scleroderma, polymyositis, dermatomyositis, mixed connective tissue disorder, rheumatoid arthritis, polymyalgia rheumatic, polychondritis, sarcoidosis and vasculitis syndromes in past/present requiring treatment		M	
7. OTHER COMORBIDITIES	<i>cmb - other</i>			
Infection 0	Documented infection, fever of unknown origin, pulmonary nodules suspicious for fungal pneumonia, positive PPD requiring current treatment with an antimicrobial (not prophylaxis) intended to continue on treatment.		N	
Moderate/severe renal 1	Serum creatinine $>$ 2 mg/dL documented on two tests, on dialysis, or prior renal transplantation		O	
Prior malignancy 2	Treated at any time point in the patient's past history, excluding nonmelanoma skin cancer. Tumors of a benign nature are not scored		P	

Comorbidities in cGVHD Scale

(Adapted from Sorrow Scale)

Study ID		Initials		Date of clinic visit	
Time point	<input type="checkbox"/> Enrollment	<input type="checkbox"/> 6 month	<input type="checkbox"/> 18 month	<input type="checkbox"/> Treatment Change	

¹ Note: BMI will be calculated from weight and height recorded elsewhere. Obesity is >35 for adults or BMI ≥95% for children

² Note: to convert creatinine from mmol/L to mg/dl, multiple mmol/L by 11.3

Total Number of Comorbidities or Secondary Conditions: cmb_tot

Abstraction from Medical Chart

Patient Status

(running log)

Study ID		Date of Review	medab_dt
Time point	<input type="checkbox"/> enrollment <input type="checkbox"/> 3 month <input type="checkbox"/> 6 month <input type="checkbox"/> 18 month <input type="checkbox"/> Treatment change medab_time <input type="checkbox"/> Annual Review: <input type="checkbox"/> year 1 <input type="checkbox"/> year 2 <input type="checkbox"/> year 3 <input type="checkbox"/> year 4 <input type="checkbox"/> year 5		
1. Date of last contact or most recent medical note:		___ / ___ / ___ MM DD YYYY	medab_last_contact
2. Select all events that have occurred since study enrollment:			
<input type="checkbox"/>	Completed study early complete_early <input type="checkbox"/> Never started new rx (ineligible) <input type="checkbox"/> Pt withdrew pt_withdraw <input type="checkbox"/> PI withdrew pi_withdraw <input type="checkbox"/> Other compl_oth	___ / ___ / ___ MM DD YYYY medab_complete_early_dt medab_rx_start_dt	
<input type="checkbox"/>	First GVHD treatment started since enrollment Which Rx started? medab_rx_start	___ / ___ / ___ MM DD YYYY	Which study visit correlates with this medication? medab_rx_visit
<input type="checkbox"/>	Second GVHD treatment started since enrollment Which Rx started? medab_rx2_start medab_rx2_code	___ / ___ / ___ MM DD YYYY medab_rx2_start_dt	Which study visit correlates with this medication? medab_rx2_visit
<input type="checkbox"/>	Third GVHD treatment started since enrollment Which Rx started? etc.	___ / ___ / ___ MM DD YYYY	Which study visit correlates with this medication?
medab_event	<input type="checkbox"/> 3	Off systemic immunosuppressive therapy	___ / ___ / ___ MM DD YYYY (date off IST) medab_offist_dt
	<input type="checkbox"/> 4	Off systemic immunosuppressive therapy for ≥12 mo and free of cGVHD symptoms	___ / ___ / ___ MM DD YYYY (confirmation date ≥12 months from date above) medab_offist_ge12mth_dt
	<input type="checkbox"/> 5	Relapse (continue to follow-up for all other events)	___ / ___ / ___ MM DD YYYY medab_rel_dt
	<input type="checkbox"/> 6	Death	___ / ___ / ___ MM DD YYYY medab_death_dt
Cause of death: medab_death_cause			
<input type="checkbox"/> 0	None of the above (confirmed by recent note)		Fill out date of last contact only.
<input type="checkbox"/> 7	Lost to follow up, no recent info		Fill out date of last contact only.

Abstraction from Medical Chart
Log of Systemic Chronic GVHD Therapy
(running log from onset of chronic GVHD)

Study ID	Initials	Date of clinic visit		
Time point	med-time	<input type="checkbox"/> Enrollment	<input type="checkbox"/> 3 month <input type="checkbox"/> 6 month <input type="checkbox"/> 18 month <input type="checkbox"/> Treatment change	
		<input type="checkbox"/> Annual review		
Med (incl ECP, PUVA)	Indication	Start Date (enter date or check box)	Current?	Stop Date (enter date or check box)
med_1 med_1_code	<input type="checkbox"/> on at time of chronic dx <input type="checkbox"/> initial Rx for chronic med_1_ind <input type="checkbox"/> 2nd Rx for chronic <input type="checkbox"/> 3rd Rx for chronic (> 3 rd Rx for chronic)	med-1_start_na <input type="checkbox"/> stopped prior to enrollment <input type="checkbox"/> started >3mo prior to enrollment Reason started: med-1_rea1	med-1_cont <input type="checkbox"/> yes <input type="checkbox"/> no	med-1_dt_stop <input type="checkbox"/> stopped prior to enrollment Reason stopped: med-1_rea2
etc.	<input type="checkbox"/> on at time of chronic dx <input type="checkbox"/> initial Rx for chronic <input type="checkbox"/> 2nd Rx for chronic <input type="checkbox"/> 3rd Rx for chronic (> 3 rd Rx for chronic)	<input type="checkbox"/> stopped prior to enrollment <input type="checkbox"/> started >3mo prior to enrollment Reason started:	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> stopped prior to enrollment Reason stopped:
	<input type="checkbox"/> on at time of chronic dx <input type="checkbox"/> initial Rx for chronic <input type="checkbox"/> 2nd Rx for chronic <input type="checkbox"/> 3rd Rx for chronic (> 3 rd Rx for chronic)	<input type="checkbox"/> stopped prior to enrollment <input type="checkbox"/> started >3mo prior to enrollment Reason started:	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> stopped prior to enrollment Reason stopped:
	<input type="checkbox"/> on at time of chronic dx <input type="checkbox"/> initial Rx for chronic <input type="checkbox"/> 2nd Rx for chronic <input type="checkbox"/> 3rd Rx for chronic (> 3 rd Rx for chronic)	<input type="checkbox"/> stopped prior to enrollment <input type="checkbox"/> started >3mo prior to enrollment Reason started:	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> stopped prior to enrollment Reason stopped:
	<input type="checkbox"/> on at time of chronic dx <input type="checkbox"/> initial Rx for chronic <input type="checkbox"/> 2nd Rx for chronic <input type="checkbox"/> 3rd Rx for chronic (> 3 rd Rx for chronic)	<input type="checkbox"/> stopped prior to enrollment <input type="checkbox"/> started >3mo prior to enrollment Reason started:	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> stopped prior to enrollment Reason stopped:
	<input type="checkbox"/> on at time of chronic dx <input type="checkbox"/> initial Rx for chronic <input type="checkbox"/> 2nd Rx for chronic <input type="checkbox"/> 3rd Rx for chronic (> 3 rd Rx for chronic)	<input type="checkbox"/> stopped prior to enrollment <input type="checkbox"/> started >3mo prior to enrollment Reason started:	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> stopped prior to enrollment Reason stopped:
	<input type="checkbox"/> on at time of chronic dx <input type="checkbox"/> initial Rx for chronic <input type="checkbox"/> 2nd Rx for chronic <input type="checkbox"/> 3rd Rx for chronic (> 3 rd Rx for chronic)	<input type="checkbox"/> stopped prior to enrollment <input type="checkbox"/> started >3mo prior to enrollment Reason started:	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> stopped prior to enrollment Reason stopped:
	<input type="checkbox"/> on at time of chronic dx <input type="checkbox"/> initial Rx for chronic <input type="checkbox"/> 2nd Rx for chronic <input type="checkbox"/> 3rd Rx for chronic (> 3 rd Rx for chronic)	<input type="checkbox"/> stopped prior to enrollment <input type="checkbox"/> started >3mo prior to enrollment Reason started:	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> stopped prior to enrollment Reason stopped:

Reason Start: A=Clinical trial; B=cGVHD worse; C=cGVHD no better; D=steroid sparing; E=prophylaxis; F=Initial cGVHD tx; G=Acute GVHD tx; H=other
Reason Stop: L=Toxicity; M=Starting another med; N=cGVHD better; O=cGVHD stable; P=disease relapse; Q=Non-compliance; R=insurance issue; S=ran out of meds; T=other

1 2 3 4 5 6 7 8
Chronic GVHD Response Measures Validation, 4.1.15, v4.1

Log of Systemic Steroid Doses

(running log starting from 1 week before enrollment)

Study ID		Initials	Date of clinic visit
Time point	<input type="checkbox"/> Enrollment <input type="checkbox"/> 3 month <input type="checkbox"/> 6 month <input type="checkbox"/> 18 month <input type="checkbox"/> Treatment change ste-time		
Steroid type	<input checked="" type="checkbox"/> Not on steroid <input type="checkbox"/> Prednisone, PO <input type="checkbox"/> Methylprednisone, PO or IV <input type="checkbox"/> Dexamethasone, PO or IV		
	4	1	2 3 ste-type
Dose Category		Start date	Stop date
<i>For QOD dosing, divide QOD dose by 2 to get daily dose. For am/pm dosing, add to get total daily dose.</i>			
<input type="checkbox"/> > 150 mg/day <input type="checkbox"/> 120-150 mg/day <input type="checkbox"/> 80-119 mg/day <input type="checkbox"/> 40-79 mg/day <input type="checkbox"/> 20-39 mg/day <input type="checkbox"/> 6-19 mg/day <input type="checkbox"/> ≤5 mg/day		ste-start	ste-stop
1 2 3 to get total daily dose.			
<input type="checkbox"/> > 150 mg/day <input type="checkbox"/> 120-150 mg/day <input type="checkbox"/> 80-119 mg/day <input type="checkbox"/> 40-79 mg/day <input type="checkbox"/> 20-39 mg/day <input type="checkbox"/> 6-19 mg/day <input type="checkbox"/> ≤5 mg/day		ste-start 2	ste-stop 2 + ste-type 2
4 5 6 7 ste-dose			
<input type="checkbox"/> > 150 mg/day <input type="checkbox"/> 120-150 mg/day <input type="checkbox"/> 80-119 mg/day <input type="checkbox"/> 40-79 mg/day <input type="checkbox"/> 20-39 mg/day <input type="checkbox"/> 6-19 mg/day <input type="checkbox"/> ≤5 mg/day		etc.	
<input type="checkbox"/> > 150 mg/day <input type="checkbox"/> 120-150 mg/day <input type="checkbox"/> 80-119 mg/day <input type="checkbox"/> 40-79 mg/day <input type="checkbox"/> 20-39 mg/day <input type="checkbox"/> 6-19 mg/day <input type="checkbox"/> ≤5 mg/day			
<input type="checkbox"/> > 150 mg/day <input type="checkbox"/> 120-150 mg/day <input type="checkbox"/> 80-119 mg/day <input type="checkbox"/> 40-79 mg/day <input type="checkbox"/> 20-39 mg/day <input type="checkbox"/> 6-19 mg/day <input type="checkbox"/> ≤5 mg/day			
<input type="checkbox"/> > 150 mg/day <input type="checkbox"/> 120-150 mg/day <input type="checkbox"/> 80-119 mg/day <input type="checkbox"/> 40-79 mg/day <input type="checkbox"/> 20-39 mg/day <input type="checkbox"/> 6-19 mg/day <input type="checkbox"/> ≤5 mg/day			
<input type="checkbox"/> > 150 mg/day <input type="checkbox"/> 120-150 mg/day <input type="checkbox"/> 80-119 mg/day <input type="checkbox"/> 40-79 mg/day <input type="checkbox"/> 20-39 mg/day <input type="checkbox"/> 6-19 mg/day <input type="checkbox"/> ≤5 mg/day			
<input type="checkbox"/> > 150 mg/day <input type="checkbox"/> 120-150 mg/day <input type="checkbox"/> 80-119 mg/day <input type="checkbox"/> 40-79 mg/day <input type="checkbox"/> 20-39 mg/day <input type="checkbox"/> 6-19 mg/day <input type="checkbox"/> ≤5 mg/day			
<input type="checkbox"/> > 150 mg/day <input type="checkbox"/> 120-150 mg/day <input type="checkbox"/> 80-119 mg/day <input type="checkbox"/> 40-79 mg/day <input type="checkbox"/> 20-39 mg/day <input type="checkbox"/> 6-19 mg/day <input type="checkbox"/> ≤5 mg/day			

Make copies if additional entries are necessary.

Chronic GVHD Protocol

Chronic GVHD response measures validation

Provider Survey

Enrollment

Instructions:

Please score all signs and symptoms. If you believe the sign or symptom is **DEFINITELY NOT** related to chronic GVHD (e.g., *C difficile* diarrhea, shingles rash, shortness of breath due to pulmonary embolus) then you should **STILL** score it, but indicate the true diagnosis.

Subjective symptoms can be scored. For example, joint tightness can be scored based on subjective findings despite the absence of objective limitations.

Please score signs and symptoms present in the *last week*.

Date of Visit:

Patient:

MRN:

Your Name:

Target Date for Next

Visit:

(+/- 1 mo for 3 or 6 mo visit; +/- 3 mos for 18 mo visit)

Confirmed Next Visit






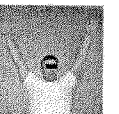
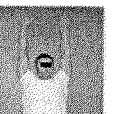
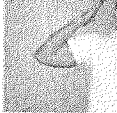







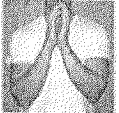
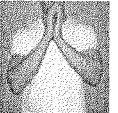
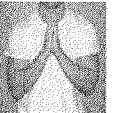
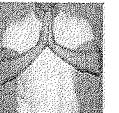
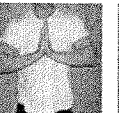


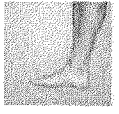
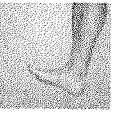
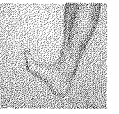
Date:

SKIN & ROM

		0	1	2	3
<p>Skin</p> <div style="border: 1px solid black; padding: 5px; margin: 5px 0;"> <u>GVHD features to be scored by BSA:</u> </div> <p><u>Check all that apply:</u></p> <div style="display: flex; flex-direction: column; gap: 5px;"> <input type="checkbox"/> Maculopapular rash / erythema <input type="checkbox"/> Lichen planus-like features <input type="checkbox"/> Sclerotic features <input type="checkbox"/> Papulosquamous lesions or ichthyosis <input type="checkbox"/> Keratosis pilaris-like </div> <p style="margin-top: 5px;"><i>sc-skin-feat</i></p>	<input type="checkbox"/> No BSA involved <i>sc-skin</i>	<input type="checkbox"/> 1-18% BSA	<input type="checkbox"/> 19-50% BSA	<input type="checkbox"/> >50% BSA	
<input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): _____ <i>sc-skin-gvhd</i>					
<p>Skin Features Score</p>	<input type="checkbox"/> No sclerotic features <i>sc-skin-sclerotic</i>		<input type="checkbox"/> Superficial sclerotic features "not hidebound" (able to pinch)	<p><u>Check all that apply</u></p> <input type="checkbox"/> Deep sclerotic features <input type="checkbox"/> "Hidebound" (unable to pinch) <input type="checkbox"/> Impaired mobility <input type="checkbox"/> Ulceration	
<p>If skin features score = 3, BSA% of non-moveable sclerosis/fasciitis <i>sc-skin-bsa</i> <i>sc-skin-sclerotic-severe</i></p> <p>How would you rate the severity of this patient's skin and/or joint tightening on the following scale, where 0 is not at all severe and 10 is the most severe symptoms possible:</p> <div style="display: flex; justify-content: space-between; align-items: center;"> <div style="text-align: center;"> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p>Symptoms not at all severe</p> </div> <div style="text-align: center; flex-grow: 1;"> <p><i>sc-skin-scale</i></p> <p>Most severe symptoms possible</p> </div> </div>					
<p>Fascia</p> <p><i>j-fascia</i></p>	<input type="checkbox"/> Normal	<input type="checkbox"/> Tight with normal areas	<input type="checkbox"/> Tight	<input type="checkbox"/> Tight, unable to move	

SKIN & ROM

Please circle this person's current ROM for each joint below:

	1 (Worst)	2	3	4	5	6	7 (Normal)	
Shoulder								<input type="checkbox"/> Not done
<i>rom - shr</i>								
Elbow								<input type="checkbox"/> Not done
<i>rom_elb</i>								
Wrist/finger								<input type="checkbox"/> Not done
<i>rom_wri</i>								
Ankle								<input type="checkbox"/> Not done
<i>rom - ank</i>								

Abnormality present but explained entirely by non-GVHD documented cause

(specify): _____

rom - gvhd

		0	1	2	3
Mouth		<input type="checkbox"/> No symptoms <i>SC-mouth</i>	<input type="checkbox"/> Mild symptoms with disease signs but not limiting oral intake significantly	<input type="checkbox"/> Moderate symptoms with disease signs with partial limitation of oral intake	<input type="checkbox"/> Severe symptoms with disease signs on examination with major limitation of oral intake
	<input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): <i>SC-mouth-gvhd</i>				
Mouth	Ulcers	<input type="checkbox"/> None <i>mouth-u</i>		<input type="checkbox"/> Ulcers involving ($\leq 20\%$)	<input type="checkbox"/> Severe ulceration ($> 20\%$)
	Erythema	<input type="checkbox"/> None <i>r-mouth-e</i>	<input type="checkbox"/> Mild erythema OR Moderate erythema ($< 25\%$)	<input type="checkbox"/> Moderate ($\geq 25\%$) OR Severe erythema ($< 25\%$)	<input type="checkbox"/> Severe erythema ($\geq 25\%$)
	Lichenoid	<input type="checkbox"/> None <i>r-mouth-lz</i>	<input type="checkbox"/> Lichen-like changes ($< 25\%$)	<input type="checkbox"/> Lichen-like changes (25-50%)	<input type="checkbox"/> Lichen-like changes ($> 50\%$)
GI Tract	<input type="checkbox"/> No symptoms <i>SC-gi</i> <input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): <i>SC-gi-gvhd</i>	<input type="checkbox"/> Symptoms without significant weight loss ($< 5\%$) over past 3 months	<input type="checkbox"/> <u>Check all that apply</u> <input type="checkbox"/> Symptoms associated with mild to moderate weight loss (5-15%) over past 3 months <input type="checkbox"/> Moderate diarrhea without significant interference with daily living <i>SC-gi-mild</i>	<input type="checkbox"/> <u>Check all that apply</u> <input type="checkbox"/> Symptoms associated with significant weight loss $> 15\%$ over past 3 months, requires nutritional supplement for most calorie needs <input type="checkbox"/> Esophageal dilation <input type="checkbox"/> Severe diarrhea with significant interference with daily living <i>SC-gi-severe</i>	
Esophagus	<input type="checkbox"/> No symptoms <i>SC-gi-e</i>	<input type="checkbox"/> Occasional dysphagia or odynophagia with solid food or pills during the past week	<input type="checkbox"/> Intermittent dysphagia or odynophagia with solid food or pills, but not for liquids or soft foods during the past week	<input type="checkbox"/> Dysphagia or odynophagia for almost all oral intake, on almost every day of the past week	
Upper GI	<input type="checkbox"/> No symptoms <i>SC-gi-u</i>	<input type="checkbox"/> Mild, occasional symptoms, with little reduction in oral intake during the past week	<input type="checkbox"/> Moderate, intermitted symptoms, with some reduction in oral intake, during the past week	<input type="checkbox"/> More severe or persistent symptoms throughout the day, with marked reduction in oral intake, on almost every day of the week	
Lower GI	<input type="checkbox"/> No loose or liquid stools during the past week <i>r-lgi</i>	<input type="checkbox"/> Occasional loose or liquid stools on some days during the past week	<input type="checkbox"/> Intermittent loose or liquid throughout the day, on almost every day of the past week, without requiring intervention to prevent or correct volume depletion	<input type="checkbox"/> Voluminous diarrhea on almost every day of the past week, requiring intervention to prevent or correct volume depletion	
	<input type="checkbox"/> Diarrhea				

	0	1	2	3
Eye	<input type="checkbox"/> No symptoms <i>SC-eye 2</i>	<input type="checkbox"/> Mild dry eye symptoms not affecting ADL (requiring eye drops ≤3x per day)	<input type="checkbox"/> Moderate dry eye symptoms partially affecting ADL WITHOUT new vision impairment due to KCS <i>Check all that apply</i> <input type="checkbox"/> Requiring lubricant eye drops >3x per day <input type="checkbox"/> Punctual plugs <i>SC-eye-moderate-2 sicca</i>	<input type="checkbox"/> Severe dry eye symptoms significantly affecting ADL <i>Check all that apply</i> <input type="checkbox"/> Special eyewear to relieve pain <input type="checkbox"/> Unable to work because of ocular symptoms <input type="checkbox"/> Loss of vision due to kerato-conjunctivitis <i>SC-eye-severe-2</i>
	<input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): _____ <i>SC-eye-gvhd</i>			
Joints /Fascia	<input type="checkbox"/> No symptoms <i>SC-joint</i>	<input type="checkbox"/> <i>Check all that apply</i> <input type="checkbox"/> Mild tightness of arms or legs <input type="checkbox"/> Mild decreased range of motion (ROM) AND not affecting ADL <i>SC-joint-mild</i>	<input type="checkbox"/> <i>Check all that apply</i> <input type="checkbox"/> Tightness of arms or legs <input type="checkbox"/> Joint contractures <input type="checkbox"/> Erythema thought due to fasciitis <input type="checkbox"/> Moderate decrease ROM AND mild to moderate limitation of ADL <i>SC-joint-moderate</i>	<input type="checkbox"/> Contractures WITH significant decrease of ROM AND significant limitation of ADL (unable to tie shoes, button shirts, dress self etc.)
	<input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): _____ <i>SC-joint-gvhd</i>			
Genital Tract <input type="checkbox"/> Not Examined	<input type="checkbox"/> No signs <i>SC-genital</i>	<input type="checkbox"/> Mild signs and females with or without discomfort on exam	<input type="checkbox"/> Moderate signs and may have symptoms with discomfort on exam	<input type="checkbox"/> Severe signs with or without symptoms
	<input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): _____ <i>SC-gen-gvhd</i>			
Lung	<input type="checkbox"/> No symptoms <i>SC-lung</i>	<input type="checkbox"/> Mild symptoms (shortness of breath after climbing one flight of steps)	<input type="checkbox"/> Moderate symptoms (shortness of breath after walking on flat ground)	<input type="checkbox"/> Severe symptoms (shortness of breath at rest; requiring O ₂)
	<input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): _____ <i>SC-lung-gvhd</i>			

Note: Liver and pulmonary function tests are collected via chart review to calculate those scores

OVERALL STATUS

Please rate the severity of this person's chronic GVHD	
on this scale →	<input type="checkbox"/> No GVHD (0) <input type="checkbox"/> Mild (1) <input type="checkbox"/> Moderate (2) <input type="checkbox"/> Severe (3) <div style="text-align: center; font-family: cursive;">md-sev-mms</div>
and on this scale → (circle one)	<div style="display: flex; justify-content: space-between;"> <div style="width: 20%;">cGVHD symptoms are not at all severe</div> <div style="width: 60%; text-align: center;"> <div style="font-family: cursive; font-size: 1.2em;">md-sev 10</div> </div> <div style="width: 20%; text-align: right;">cGVHD symptoms are most severe possible</div> </div> <div style="text-align: center; margin-top: 5px;"> 0 1 2 3 4 5 6 7 8 9 10 </div>

Current GVHD Status	<input type="checkbox"/> Complete response (1)	<input type="checkbox"/> Partial response (2)	<input type="checkbox"/> Mixed response (3)	<input type="checkbox"/> Unchanged (4)	<input type="checkbox"/> Progressive (5)	<input type="checkbox"/> Too soon to tell (6) <small>(Enrollment is ≤ 2 weeks from dx)</small>

Does this person <i>currently</i> have:	<input type="checkbox"/> Late acute GVHD (1) <input type="checkbox"/> Overlap acute and chronic GVHD (2) <input type="checkbox"/> Classic chronic GVHD (3) <input type="checkbox"/> No GVHD (0)
<div style="font-family: cursive; font-size: 1.2em;">gvhd - current</div>	

What new medication or treatment was started in the past 4 weeks or will start in the next 4 weeks?

md-surv-new-med

Reason for new treatment? (check all that apply)

- 1 New symptoms/organ manifestation
- 2 Progression of prior involvement
- 3 Lack of improvement in GVHD
- 4 "Steroid-sparing"
- 5 Toxicity to prior agents
- 6 Clinical trial available
- 99 Other reason, specify _____

md-surv-new-med-reas

OVERALL STATUS FOLLOW UP VERSION

Please rate the severity of this person's chronic GVHD

on this scale →	<input type="checkbox"/> No GVHD (0) <input type="checkbox"/> Mild (1) <input type="checkbox"/> Moderate (2) <input type="checkbox"/> Severe (3)
and on this scale → <i>(circle one)</i>	<div style="display: flex; justify-content: space-between;"> <div style="width: 20%;">cGVHD symptoms are not at all severe</div> <div style="width: 60%; text-align: center;"> </div> <div style="width: 20%; text-align: right;">cGVHD symptoms are most severe possible</div> </div>

gvhd-status

Current GVHD Status	<input type="checkbox"/> Complete response (1)	<input type="checkbox"/> Partial response (2)	<input type="checkbox"/> Mixed response (3)	<input type="checkbox"/> Unchanged (4)	<input type="checkbox"/> Progressive (5)
----------------------------	--	---	---	--	--

Does this person currently have:	<input type="checkbox"/> Late acute GVHD (1) <input type="checkbox"/> Overlap acute and chronic GVHD (2) <input type="checkbox"/> Classic chronic GVHD (3) <input type="checkbox"/> No GVHD (0)
---	--

Since the enrollment visit on _____, how would you say this patient's chronic GVHD has changed?

	Never involved (0)	Completely gone (1)	Very much better (2)	Moderately better (3)	A little better (4)	About the same (5)	A little worse (6)	Moderately worse (7)	Very much worse (8)
<i>md-chg-</i> Mouth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>md-chg-</i> Skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>md-chg-</i> Eyes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>md-chg-</i> Joints	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>md-chg-</i> Lungs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>md-chg-</i> Upper GI <i>vgi</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>md-chg-</i> Lower GI <i>lgi</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>md-chg-</i> Liver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>md-chg-</i> cGVHD		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>md-chg-</i> Overall		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What are your reasons for how you rated "chronic GVHD overall"? <div style="text-align: right;"><i>Write in</i> →</div>	(For example, has a specific organ or symptom improved or worsened?) <div style="text-align: center;"><i>md-chg-gvhd-reas</i></div>
---	--

OVERALL STATUS

Other complications related to chronic GVHD					
	Never (0)	Past, not now (1)	Mild (2)	Moderate (3)	Severe (4)
1. Bronchiolitis obliterans syndrome <i>cm1</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Joint contractures <i>cm2</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Fasciitis <i>cm3</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Severe dry eyes <i>cm4</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Nephrotic syndrome <i>cm5</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Esophageal stricture or web <i>cm6</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Serositis (ascites, pericardial effusion, pleural effusion) <i>cm7</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Other, please specify: <i>cm-oth</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

For office use only:

Study ID	Initials (First, Last)	Date completed:	Date received:
Person completing form:		Their degree:	
Timepoint:	<input type="checkbox"/> Enrollment <input type="checkbox"/> 6 Months <input type="checkbox"/> 3 Months <input type="checkbox"/> New Rx <input type="checkbox"/> 18 Months	Date entered:	

Chronic GVHD Patient Survey ENROLLMENT/{FOLLOW-UP}

INSTRUCTIONS

This survey will provide us with important information about your health.

All your answers will be kept strictly confidential and will not be included in your medical record. The information that you provide will be combined with that of many other transplant patients before analysis.

Please read each question carefully. Circle or check off the answer that best describes how you feel.

While we ask that you answer each question, you are free to *not* answer any question that makes you feel uncomfortable. If none of the answers provided seems exactly right, choose the one that comes closest to being right for you. Some of the questions may seem the same. However, it is important that we ask about certain aspects of your health in different ways in order to fully understand how you are feeling.

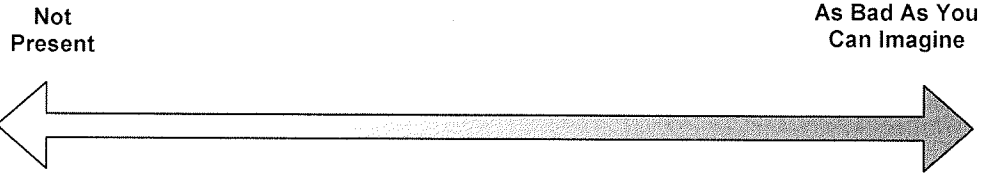
When you have completed this survey, please give it back to the study coordinator or mail it back to us using the enclosed self-addressed, stamped envelope.

We greatly appreciate your participation.

Your name: _____ **Date:** _____

Section 1: Your Chronic Graft vs. Host Disease (GVHD) Symptoms

Please circle the number that shows how severe your symptoms have been **in the last week:**



PSR	1.	Your chronic GVHD symptoms overall?	0	1	2	3	4	5	6	7	8	9	10
PSR	2.	Your skin itching at its WORST?	0	1	2	3	4	5	6	7	8	9	10
PSR	3 [^]	Your skin and/or joint tightening at their WORST?	0	1	2	3	4	5	6	7	8	9	10
	4.	Your mouth sensitivity at its WORST?	0	1	2	3	4	5	6	7	8	9	10
	5.	Your genital discomfort at its WORST?	0	1	2	3	4	5	6	7	8	9	10

*Women – vagina, vulva, or labia
*Men – penis

PSR3

Overall, how would you rate the severity of your chronic GVHD?

- 0- None
- 1- Mild
- 2- Moderate
- 3- Severe

{Follow up}

Compared to your enrollment visit on _____, how would you rate your chronic GVHD symptoms now?									
	Never involved with chronic GVHD (0)	Completely gone (1)	Very much better (2)	Moderately better (3)	A little better (4)	About the same (5)	A little worse (6)	Moderately worse (7)	Very much worse (8)
Mouth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eyes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Joints	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lungs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stomach	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intestines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chronic GVHD Overall	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

pt - chg - mouth

pt - chg - skin

pt - chg - joint

pt - chg - lung

pt - chg - stomach

pt - chg - intestines

pt - chg - gvhd :

Chronic GVHD Response Measures Validation

By circling one (1) number per line, please indicate how much you have been bothered by the following problems in the past month:

SKIN:		Not at all	Slightly	Moderately	Quite a bit	Extremely
SX	1. Abnormal skin color.....	0	1	2	3	4
SX	2. Rashes.....	0	1	2	3	4
SX	3. Thickened skin.....	0	1	2	3	4
	4. Sores on skin.....	0	1	2	3	4
	5. Itchy skin.....	0	1	2	3	4
EYES AND MOUTH:		Not at all	Slightly	Moderately	Quite a bit	Extremely
	6. Dry eyes.....	0	1	2	3	4
	7. Need to use eye drops frequently..	0	1	2	3	4
	8. Difficulty seeing clearly.....	0	1	2	3	4
	9. Need to avoid certain foods due to mouth pain.....	0	1	2	3	4
	10. Ulcers in mouth.....	0	1	2	3	4
	11. Receiving nutrition from an intravenous line or feeding tube....	0	1	2	3	4
BREATHING:		Not at all	Slightly	Moderately	Quite a bit	Extremely
	12. Frequent cough.....	0	1	2	3	4
	13. Colored sputum.....	0	1	2	3	4
	14. Shortness of breath with exercise..	0	1	2	3	4
	15. Shortness of breath at rest.....	0	1	2	3	4
	16. Need to use oxygen.....	0	1	2	3	4

EATING AND DIGESTION:		Not at all	Slightly	Moderately	Quite a bit	Extremely
SX 17.	Difficulty swallowing solid foods....	0	1	2	3	4
18.	Difficulty swallowing liquids.....	0	1	2	3	4
19.	Vomiting.....	0	1	2	3	4
20.	Weight loss.....	0	1	2	3	4
MUSCLES AND JOINTS:		Not at all	Slightly	Moderately	Quite a bit	Extremely
21.	Joint and muscle aches.....	0	1	2	3	4
22.	Limited joint movement.....	0	1	2	3	4
23.	Muscle cramps.....	0	1	2	3	4
24.	Weak muscles.....	0	1	2	3	4
ENERGY:		Not at all	Slightly	Moderately	Quite a bit	Extremely
25.	Loss of energy.....	0	1	2	3	4
26.	Need to sleep more/take naps.....	0	1	2	3	4
27.	Fevers.....	0	1	2	3	4
MENTAL AND EMOTIONAL:		Not at all	Slightly	Moderately	Quite a bit	Extremely
28.	Depression.....	0	1	2	3	4
29.	Anxiety.....	0	1	2	3	4
30.	Difficulty sleeping.....	0	1	2	3	4

Section 2: Quality of Your Life After Your Transplant

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days:

PHYSICAL WELL-BEING:

		Not at all	A little bit	Some-what	Quite a bit	Very much
1.	I have a lack of energy	0	1	2	3	4
2.	I have nausea.....	0	1	2	3	4
3.	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
4.	I have pain	0	1	2	3	4
5.	I am bothered by side effects of treatment.....	0	1	2	3	4
6.	I feel ill.....	0	1	2	3	4
7.	I am forced to spend time in bed	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days:

SOCIAL/FAMILY WELL-BEING:

		Not at all	A little bit	Some-what	Quite a bit	Very much
8.	I feel close to my friends	0	1	2	3	4
9.	I get emotional support from my family.....	0	1	2	3	4
10.	I get support from my friends.....	0	1	2	3	4
11.	My family has accepted my illness	0	1	2	3	4
12.	I am satisfied with family communication about my illness.....	0	1	2	3	4
13.	I feel close to my partner (or the person who is my main support).....	0	1	2	3	4

Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box and go to the next section. -3

14.	I am satisfied with my sex life	0	1	2	3	4
-----	---------------------------------------	---	---	---	---	---

EMOTIONAL WELL-BEING:

		Not at all	A little bit	Some-what	Quite a bit	Very much
F 15.	I feel sad.....	0	1	2	3	4
16.	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
17.	I am losing hope in the fight against my illness.....	0	1	2	3	4
18.	I feel nervous.....	0	1	2	3	4
19.	I worry about dying.....	0	1	2	3	4
20.	I worry that my condition will get worse.....	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

FUNCTIONAL WELL-BEING:

		Not at all	A little bit	Some-what	Quite a bit	Very much
21.	I am able to work (include work at home).....	0	1	2	3	4
22.	My work (include work at home) is fulfilling.....	0	1	2	3	4
23.	I am able to enjoy life.....	0	1	2	3	4
24.	I have accepted my illness.....	0	1	2	3	4
25.	I am sleeping well.....	0	1	2	3	4
26.	I am enjoying the things I usually do for fun.....	0	1	2	3	4
27.	I am content with the quality of my life right now....	0	1	2	3	4

Section 3: Your Health and Well-Being

This section asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Please answer every question. If you are unsure about how to answer a question, please give the answer that seems closest to how you feel.

For each of the following questions, please mark an in the one box that best describes your answer.

KPS 1. Which statement describes how you feel most of the time? (please check one)

- 1. Normal, no difficulties with daily activities
- 2. Able to carry on normal activities, minor problems
- 3. Normal activity with effort
- 4. Able to care for self, but unable to carry on normal activity or active work
- 5. Require occasional assistance, but able to care for most of needs
- 6. Require considerable assistance and frequent medical care
- 7. Disabled, require special care and assistance
- 8. Severely disabled, hospitalized
- 9. Very sick, hospitalized

SF 2. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

SF 3. Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

Yes, limited a lot Yes, limited a little No, not limited at all

▼ ▼ ▼

SF



- | | | | |
|--|--------|--------|--------|
| 4. <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports | 1..... | 2..... | 3..... |
| 5. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | 1..... | 2..... | 3..... |
| 6. Lifting or carrying groceries | 1..... | 2..... | 3..... |
| 7. Climbing <u>several</u> flights of stairs | 1..... | 2..... | 3..... |
| 8. Climbing <u>one</u> flight of stairs | 1..... | 2..... | 3..... |
| 9. Bending, kneeling, or stooping | 1..... | 2..... | 3..... |
| 10. Walking <u>more than a mile</u> | 1..... | 2..... | 3..... |
| 11. Walking <u>several hundred yards</u> | 1..... | 2..... | 3..... |
| 12. Walking <u>one hundred yards</u> | 1..... | 2..... | 3..... |
| 13. Bathing or dressing yourself | 1..... | 2..... | 3..... |

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼

- SF 14. Cut down on the amount of time you spent on work or other activities..... 1.....2.....3.....4.....5
15. Accomplished less than you would like..... 1.....2.....3.....4.....5
16. Were limited in the kind of work or other activities 1.....2.....3.....4.....5
17. Had difficulty performing the work or other activities (for example, it took extra effort) 1.....2.....3.....4.....5

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼

18. Cut down on the amount of time you spent on work or other activities 1.....2.....3.....4.....5
19. Accomplished less than you would like 1.....2.....3.....4.....5
20. Did work or other activities less carefully than usual 1.....2.....3.....4.....5

- SF 21. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

- SF 22. How much bodily pain have you had during the past 4 weeks?

None	Very mild	Mild	Moderate	Severe	Very Severe
▼	▼	▼	▼	▼	▼
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆

- SF 23. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼

SF

- 24. Did you feel full of life?..... 1..... 2..... 3..... 4..... 5
- 25. Have you been very nervous? 1..... 2..... 3..... 4..... 5
- 26. Have you felt so down in the dumps that nothing could cheer you up? 1..... 2..... 3..... 4..... 5
- 27. Have you felt calm and peaceful? 1..... 2..... 3..... 4..... 5
- 28. Did you have a lot of energy? 1..... 2..... 3..... 4..... 5
- 29. Have you felt downhearted and depressed?..... 1..... 2..... 3..... 4..... 5
- 30. Did you feel worn out? 1..... 2..... 3..... 4..... 5
- 31. Have you been happy? 1..... 2..... 3..... 4..... 5
- 32. Did you feel tired?..... 1..... 2..... 3..... 4..... 5



SF 33. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼
□ ₁	□ ₂	□ ₃	□ ₄	□ ₅

How TRUE or FALSE is each of the following statements for you?

SF



	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
	▼	▼	▼	▼	▼
34. I seem to get sick a little easier than other people	1	2	3	4	5
35. I am as healthy as anybody I know.....	1	2	3	4	5
36. I expect my health to get worse.....	1	2	3	4	5
37. My health is excellent.....	1	2	3	4	5

Section 4: Your Activity Level

Please check each activity according to these directions:

Check Column 1 ("Still Doing This Activity") if you completed the activity unassisted the last time you had the need or opportunity to do so.

Check Column 2 ("Have Stopped Doing This Activity") if you have engaged in the activity in the past, but you probably would not perform the activity today even if the opportunity should arise.

Check Column 3 ("Never Did This Activity") if you have never engaged in the specific activity.

		Still Doing This Activity (1)	Have Stopped Doing This Activity (2)	Never Did This Activity (3)
H	1. Getting in and out of chairs or bed (without assistance)			
H	2. Listening to the radio			
H	3. Reading books, magazines or newspapers			
	4. Writing (letters, notes)			
	5. Working at a desk or table			
	6. Standing (for more than one minute)			
	7. Standing (for more than five minutes)			
	8. Dressing or undressing (without assistance)			
	9. Getting clothes from drawers or closets			
	10. Getting in or out of a car (without assistance)			
	11. Dining at a restaurant			
	12. Playing cards/table games			
	13. Taking a bath (no assistance needed)			
	14. Putting on shoes, stockings or socks (no assistance needed)			
	15. Attending a movie, play, church event or sports activity			
	16. Walking 30 yards (27 meters)			

H

	Still Doing This Activity (1)	Have Stopped Doing This Activity (2)	Never Did This Activity (3)
17. Walking 30 yards (non-stop)			
18. Dressing/undressing (no rest or break needed)			
19. Using public transportation or driving a car (100 miles or less)			
20. Using public transportation or driving a car (99 miles or more)			
21. Cooking your own meals			
22. Washing or drying dishes			
23. Putting groceries on shelves			
24. Ironing or folding clothes			
25. Dusting/polishing furniture or polishing cars			
26. Showering			
27. Climbing six steps			
28. Climbing six steps (non-stop)			
29. Climbing nine steps			
30. Climbing 12 steps			
31. Walking ½ block on level ground			
32. Walking ½ block on level ground (non-stop)			
33. Making a bed (not changing sheets)			
34. Cleaning windows			
35. Kneeling, squatting to do light work			
36. Carrying a light load of groceries			
37. Climbing nine steps (non-stop)			

V

Chronic GVHD Response Measures Validation

H
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	Still Doing This Activity (1)	Have Stopped Doing This Activity (2)	Never Did This Activity (3)
38. Climbing 12 steps (non-stop)			
39. Walking ½ block uphill			
40. Walking ½ block uphill (non-stop)			
41. Shopping (by yourself)			
42. Washing clothes (by yourself)			
43. Walking one block on level ground			
44. Walking two blocks on level ground			
45. Walking one block on level ground (non-stop)			
46. Walking two blocks on level ground (non-stop)			
47. Scrubbing (floors, walls or cars)			
48. Making beds (changing sheets)			
49. Sweeping			
50. Sweeping (five minutes non-stop)			
51. Carrying a large suitcase or bowling (one line)			
52. Vacuuming carpets			
53. Vacuuming carpets (five minutes non-stop)			
54. Painting (interior/exterior)			
55. Walking six blocks on level ground			
56. Walking six blocks on level ground (non-stop)			
57. Carrying out the garbage			
58. Carrying a heavy load of groceries			

H

	Still Doing This Activity (1)	Have Stopped Doing This Activity (2)	Never Did This Activity (3)
59. Climbing 24 steps			
60. Climbing 36 steps			
61. Climbing 24 steps (non-stop)			
62. Climbing 36 steps (non-stop)			
63. Walking one mile			
64. Walking one mile (non-stop)			
65. Running 110 yards (100 meters) or playing softball/baseball			
66. Dancing (social)			
67. Doing calisthenics or aerobic dancing (5 minutes non-stop)			
68. Mowing the lawn (power mower, but not a riding mower)			
69. Walking two miles			
70. Walking two miles (non-stop)			
71. Climbing 50 steps			
72. Shoveling, digging or spading			
73. Shoveling, digging or spading (five minutes non-stop)			
74. Climbing 50 steps (non-stop)			
75. Walking three miles or golfing 18 holes without a riding cart			
76. Walking three miles (non-stop)			
77. Swimming 25 yards			
78. Swimming 25 yards (non-stop)			



Chronic GVHD Response Measures Validation

	Still Doing This Activity (1)	Have Stopped Doing This Activity (2)	Never Did This Activity (3)
H 79. Bicycling one mile			
80. Bicycling two miles			
81. Bicycling one mile (non-stop)			
82. Bicycling two miles (non-stop)			
83. Running or jogging ¼ mile			
84. Running or jogging ½ mile			
85. Playing tennis or racquetball			
86. Playing basketball (game play)			
87. Running or jogging ¼ mile (non-stop)			
88. Running or jogging ½ mile (non-stop)			
89. Running or jogging one mile			
90. Running or jogging two miles			
91. Running or jogging three miles			
92. Running or jogging one mile in 12 minutes or less			
93. Running or jogging two miles in 20 minutes or less			
94. Running or jogging three miles in 30 minutes or less			

Section 4: About Yourself {enrollment only}

1. What is your current work status? (circle all that apply) SD-work
- In school full time 1
 - In school part time 2
 - Working full time 3
 - Working part time 4
 - Homemaker 5
 - Retired 6
 - On medical leave from work 7
 - Disabled, unable to work 8
 - Unemployed, looking for work 9
 - Unemployed, not looking for work 10
 - Other, specify sd-work-oth 12

2. Do you consider yourself to be Latino(a) or Hispanic? sd-ethnicity
- No, not Latino/Hispanic 1
 - Yes, Latino/Hispanic 2

3. How would you best describe your race? (Circle all that apply): sd-race
- Black 1
 - American Indian/Alaskan Native 2
 - Asian 3
 - Hawaiian Native/Pacific Islander 4
 - White 5
 - Other, specify sd-race-oth 6

4. What is your gender? sd-gen
- Male 1
 - Female 2

5. How old are you? sd-age years

6. How much did you weigh before your transplant? sd-wt
- Please be sure to indicate if in pounds (lbs) or kilograms (kg).

7. What is your marital status? sd-marital
- Married/Living with partner 1
 - Single, Never married 2
 - Divorced, Separated 3
 - Widowed 4
 - Other, specify sd-marital-oth 5

8. What is the highest grade of school you have completed? sd-educ
- Grade school 1
 - Some high school 2
 - High school graduate 3
 - Some college 4
 - College graduate 5
 - Post graduate degree 6

9. What was your approximate annual family income in the year before you had your transplant? sd-income
- Under \$15,000 1
 - \$15,000 - \$24,999 2
 - \$25,000 - \$49,999 3
 - \$50,000 - \$74,999 4
 - \$75,000 - \$99,999 5
 - \$100,000 or above 6

10. Help us stay in contact with you if you move! We will need to stay in touch with you over the next several years, so please provide the name, address and phone number of a person **NOT LIVING WITH YOU** who will always know where you are, and who would be willing to let us contact them should we have trouble reaching you (for example, a parent, child or good friend who *lives separately from you*). Please be sure that they give permission for us to contact them for this purpose.

Name: _____

Address: _____

Phone: _____

Relationship to you: _____

11. Would you like us to contact you about research studies related to chronic GVHD in the future? We would tell you more about the study at the time and you would be free to say yes or no.

Yes please contact me

No thanks *SP-Future*

Thank you for participating in this study

Please remember that someone is available to speak with you at any time, if you wish.

Dr. <<Site PI>> may be reached by calling <<Site PI phone>>. (S)he will be able to answer any questions about the study or refer you to other support staff as needed.

Please use the space below for any other comments.

For office use only:

Study ID	Initials (First, Last)	Date completed:	Date received:
Timepoint:	<input type="checkbox"/> Enrollment <input type="checkbox"/> 6 Months <input type="checkbox"/> 18 Months	Date entered:	
	<input type="checkbox"/> 3 Months <input type="checkbox"/> New Rx	v1.0	

Sample Collection

Study ID		Date of clinic visit		Date of blood draw	<i>spe-dt</i>
Time Point				Study Site	
<input type="checkbox"/> Enrollment <input type="checkbox"/> 3 month <input type="checkbox"/> 6 month <input type="checkbox"/> 18 month <input type="checkbox"/> Treatment change <input type="checkbox"/> Out of window visit (>7 months)		<i>spe-visit-type</i>		<input type="checkbox"/> Fred Hutchinson Cancer Research Center <input type="checkbox"/> University of Minnesota <input type="checkbox"/> Dana-Farber Cancer Institute <input type="checkbox"/> Stanford University <input type="checkbox"/> Vanderbilt University <input type="checkbox"/> H. Lee Moffitt Cancer Center <input type="checkbox"/> Roswell Park Cancer Institute <input type="checkbox"/> Cleveland Clinic <input type="checkbox"/> Ohio State University <input type="checkbox"/> University of British Columbia <input type="checkbox"/> Duke University <input type="checkbox"/> MD Anderson	
Reason Sample is Missing		<input type="checkbox"/> Participant missed study visit <input type="checkbox"/> Participant/parent refused <input type="checkbox"/> Lab unable to obtain sample <input type="checkbox"/> Unable to contact participant <input type="checkbox"/> Illness <input type="checkbox"/> Other, specify: <div style="margin-left: 20px;"><i>sample-miss-oth</i></div>			
<i>sample-miss-reas</i>					

Sample Collection

Study ID		Date of clinic visit		Date of blood draw	<i>spe-dt</i>	Time of draw	<i>spe-time</i>
Time Point				Study Site			
<input type="checkbox"/> Enrollment <input type="checkbox"/> 3 month <input type="checkbox"/> 6 month <input type="checkbox"/> 18 month <input type="checkbox"/> Treatment change <input type="checkbox"/> Out of window visit (>7 months)				<input type="checkbox"/> Fred Hutchinson Cancer Research Center <input type="checkbox"/> University of Minnesota <input type="checkbox"/> Dana-Farber Cancer Institute <input type="checkbox"/> Stanford University <input type="checkbox"/> Vanderbilt University <input type="checkbox"/> H. Lee Moffitt Cancer Center <input type="checkbox"/> Roswell Park Cancer Institute <input type="checkbox"/> Cleveland Clinic <input type="checkbox"/> Ohio State University <input type="checkbox"/> University of British Columbia <input type="checkbox"/> Duke University <input type="checkbox"/> MD Anderson			
Root barcode (123-456-7)	<i>barcode</i>	# of heparin plasma aliquots	<i>heparin-plasma</i>	# of PBMC aliquots	<i>pbmc</i>		

Plasma

mhl_oth

mhl
mhz
↓

Mh1	<input type="checkbox"/> Not collected	<input type="checkbox"/> 1 ml	<input type="checkbox"/> 0.5 ml	<input type="checkbox"/> ___ ml
Mh2	<input type="checkbox"/> Not collected	<input type="checkbox"/> 1 ml	<input type="checkbox"/> 0.5 ml	<input type="checkbox"/> ___ ml
Mh3	<input type="checkbox"/> Not collected	<input type="checkbox"/> 1 ml	<input type="checkbox"/> 0.5 ml	<input type="checkbox"/> ___ ml
Mh4	<input type="checkbox"/> Not collected	<input type="checkbox"/> 1 ml	<input type="checkbox"/> 0.5 ml	<input type="checkbox"/> ___ ml
Mh5	<input type="checkbox"/> Not collected	<input type="checkbox"/> 1 ml	<input type="checkbox"/> 0.5 ml	<input type="checkbox"/> ___ ml
Mh6	<input type="checkbox"/> Not collected	<input type="checkbox"/> 1 ml	<input type="checkbox"/> 0.5 ml	<input type="checkbox"/> ___ ml
Mh7	<input type="checkbox"/> Not collected	<input type="checkbox"/> 1 ml	<input type="checkbox"/> 0.5 ml	<input type="checkbox"/> ___ ml
Mh8	<input type="checkbox"/> Not collected	<input type="checkbox"/> 1 ml	<input type="checkbox"/> 0.5 ml	<input type="checkbox"/> ___ ml
Mh9	<input type="checkbox"/> Not collected	<input type="checkbox"/> 1 ml	<input type="checkbox"/> 0.5 ml	<input type="checkbox"/> ___ ml
Mh10	<input type="checkbox"/> Not collected	<input type="checkbox"/> 1 ml	<input type="checkbox"/> 0.5 ml	<input type="checkbox"/> ___ ml
Mh11	<input type="checkbox"/> Not collected	<input type="checkbox"/> 1 ml	<input type="checkbox"/> 0.5 ml	<input type="checkbox"/> ___ ml
Mh12	<input type="checkbox"/> Not collected	<input type="checkbox"/> 1 ml	<input type="checkbox"/> 0.5 ml	<input type="checkbox"/> ___ ml
Comments: <i>hep-comments</i>				

PBMC

cl_oth

cl
↓

C1	<input type="checkbox"/> Not collected	<input type="checkbox"/> 5 million	<input type="checkbox"/> 2 million	<input type="checkbox"/> ___ cells
C2	<input type="checkbox"/> Not collected	<input type="checkbox"/> 5 million	<input type="checkbox"/> 2 million	<input type="checkbox"/> ___ cells
C3	<input type="checkbox"/> Not collected	<input type="checkbox"/> 5 million	<input type="checkbox"/> 2 million	<input type="checkbox"/> ___ cells
C4	<input type="checkbox"/> Not collected	<input type="checkbox"/> 5 million	<input type="checkbox"/> 2 million	<input type="checkbox"/> ___ cells
C5	<input type="checkbox"/> Not collected	<input type="checkbox"/> 5 million	<input type="checkbox"/> 2 million	<input type="checkbox"/> ___ cells
C6	<input type="checkbox"/> Not collected	<input type="checkbox"/> 5 million	<input type="checkbox"/> 2 million	<input type="checkbox"/> ___ cells
C7	<input type="checkbox"/> Not collected	<input type="checkbox"/> 5 million	<input type="checkbox"/> 2 million	<input type="checkbox"/> ___ cells
C8	<input type="checkbox"/> Not collected	<input type="checkbox"/> 5 million	<input type="checkbox"/> 2 million	<input type="checkbox"/> ___ cells
Comments: <i>pbmc-comments</i>				

pbmc-actual = actual cell count