	arrow Donor Program [®] Death Information	Unrelated	Recipient NMDP ID:
		Recipient	
	Registry Use Only	Last Name:	
ence		Recipient Local ID (optional)	
mber:			
-		Today's Date:	Day Year TC Ccde:
te ceived:		Month E Product type for first transpla	
L			DEATH
a he com	pleted in conjunction with a	100-Day Follow-Up Form (Form	130, 530, 630), Six Month to Two Year
			-Up Farm (Form 150, 550, 650).
I. Date of d	leath:		Cause of Death Codes
		YEar DEATHD7	1.0 Graft rejection or failure
. Was caus	se of death confirmed by autops;		Infection (other than interstitial pneumoni
1 🗆 yes	A 1 3 Januar - A Jan - 1		2.1 Bacterial 2.2 Fungal
2 🗆 no 3 🗆 pend	AUTORSY		2.3 Viral
•	- ·		2.4 Protozoal 2.5 Organism not identified
		e of death code below. List in order o	f 2.5 Other, specify
	ng severity, i.e., primary cause fir d, write the cause in the space p	st. If a code number for "Other, spec rovided)	
is entered	, while the cause in the space p		3.1 Viral, CMV 3.2 Viral, other
P	rimary: . Spe	cify:	3.3 Pheumocystis
DCAU	set		3.4 Idiopathic 3.5 Other, specify
DCAW	< <u>C</u>	cify:	4.0 Adult Respiratory Distress Syndrom
JAAV	[] []		5.0 Acute GVHD
DCAU	SE3 Spe	cify:	5.0 Chronic GVHD
		cify:	7.0 Recurrence or persistence of leukemia/malignancy/MDS
DCAN	SG4 . Sper	City	Organ failure (not due to GVHD or infection
		cify:	8.1 Liver
DCA1	ASES Spe	city	
L			8.4 CNS
DCA	MSE6 . Sper	cify:	8.5 Renal 8.6 Multiple organ failure, specify
			8.7 Other, specify
. Signed: _		n completing form	9.0 Secondary malignancy
Please pr	int name:		10.1 Pulmonary
·			10.2 Intracranial 10.3 Gastrointestinal
Phone nu	mber. ()		10.4 Hemorrhage not specified 10.5 Other, specify
Fay numb			
I GA HUMB			11.1 Thrombaembolic
E-mail ad	dress:		
			11.3 Gastrointestinal
			11.4 Thrombotic thrombocytopenic purpura
a copy o	f this form to: Registry, Suite 500,		11.5 Vascular not specified
AND NIMPLE	Registry, Suite 500,	ant 1 1 1 4 4 1	11.6 Other, specify
3001 8-020	turan Stroop N E Minnosanlie I		
2001 Broad	tway Street N.E., Minneapolis, I al at the transplant center.	VIN 33413	12.0 Accidental death

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TCD	DONOR INF	ORMATION REQU	EST	DONRINFO
T Cell Depletion Trial MCC Use Only Date Rcvd.:		Recipient NMDP ID: TCD Name Code: Center Code:		
1. Donor gender DI d	GEN DER			1 🗆 Male 2 🗔 Female
2. Donor age	AGE		•••••	years
Birth date DEC	BRTH DT	м	D	Y Not known
3. Donor ethnicity			•••••	99 🗆 Not known
Caucasian/White 1 European or 1 2 Middle East or Africa 3 White, Otherw Black African Ameri 5 African Black born in Africa 6 Caribbean Black 7 South or Cen 8 Black, Otherw	Western Russia Ir North Coast of vise not specified can (both parents ack tral American Black	Asian/Pacific Islander 9 Asian Indian 10 Filipino 11 Hawaiian (Polynesian) 12 Japanese 13 Korean 14 Northem Chinese 15 Southeast Asian/Southern Chinese 16 Asian/Pacific Islander, Otherwise not specified Hispanic 17 Caribbean Hispanic	19 1 20 1 Native / 21 1 22 2 23 1 0 Other	Mexican or Southwestern USA Hispanic South or Central American Hispanic Hispanic, Otherwise not specified American Native Alaskan/Eskimo/Aleut Tribe: American Indian Tribe: Antive American, Otherwise not specified Other, specity
4. Donor testing for evidence of	of prior cytomegalov	•		VTST .
1 Positive	2 Negative	3□ Inconclusive	•	4□ Not Tested
Comments:				
Signature	TCE	Certification No.		Date

TCD	
T Cell Depletion Trial	

ELIGIBILITY FORM

٩,



	Recipient NMDP ID:
MCC Use Or	TCD Name Code:
Date Rcvd.:	Center Code:
Patient Status	
1. Date of birth	
	\rightarrow 3. Is the patient pregnant or breastfeeding?
4. Has the patient had	a previous autologous or allogeneic bone marrow transplant?
5. Does the patient ha	ve a consenting suitably HLA-matched related donor? RELDONR 1 🗆 Yes 2 🗆 No
	ve a history of Myelodysplastic Syndrome? MYELODY S 1 🗆 Yes 2 🗆 No
7. What is the patient's	primary disease?
1 □ Acute → Myelogenous Leukemia (with or without history of MDS)	 8. Is the patient in first complete remission (< 5% blasts in marrow) with translocations t(8;21)? AMLCR 1 □ Yes → 8a. Has the patient failed first line induction therapy? 2 □ No 1 □ Yes 2 □ No 4 Continue with question 25
DI SPRIM	 9. Is the patient in first complete remission (≤ 5% blasts in marrow) with translocations t(15;17) or 16q abnormality? TRANSLOC Yes → 9a. Has the patient failed first line induction therapy? No Yes 2 □ No AMLINDCT Continue 9b. Does the patient have molecular evidence of disease? with Yes 2 □ No AMLMOLEC 25 Continue with question 25

Primary diseases (question 7) are continued on page 2

ELIGIBILITY FORM (Continued)

Recipient NMDP ID:

2
Acute Is the patient in first complete remission (< 5% blasts in marrow)? 10. Lymphoblastic ALLCR Leukemia 11. Does patient have hypoploidy as measured HYPC $1 \square \text{Yes} \rightarrow$ 2 🗆 No by flow cytometry? I 🗆 Yes 2 🗆 No 12. Does the patient have pseudodiploidy PSEUDO with translocations t(9;22), t(4;11), Continue or t(8;14)? 1 □ Yes 2 🗆 No with question 13. Record the WBC at presentation . ⊣/mm³ 25 WBC 14. Did the patient achieve a complete remission after 4 weeks of induction therapy? 1 🗆 Yes 2 🗆 No ALLINDCT Continue with question 25 3 🗌 Chronic CLMBLAST 15. Is the patient in blast crisis (>30% promyelocytes Myelogenous plus blasts in their bone marrow)? 1 🗆 Yes 2 🗆 No Leukemia Continue with question 25 4 🗌 Lympho-16. What is the Lymphoblastic Lymphoma staging level? blastic Lymphoma 4 □ Stage 4 LUSTACIE 1 🗆 Stage 1 2 🗆 Stage 2 3 🗆 Stage 3 Continue with question 25 5 \Box Undifferentiated Leukemia \rightarrow Continue with question 25 6 🗆 Biphenotypic Leukemia \rightarrow Continue with question 25 7 🗌 Juvenile 17. Are either of the following cytogenetic abnormalities present? $CML \rightarrow$ 7g JCML7Q. 1 🗆 Yes $2 \square No$ Infantile monosomy 7 JCMLJNM7 1 □ Yes 2 🗆 No 18. Record leukocytosis with absolute monocytosis JCMLLEUK ⊔ uL JCMLEMMY 19. Are immature myeloid cells present in the peripheral circulation? . 1 Ves 2 No Continue with question 25

Primary diseases (question 7) are continued on page 3

TCD

TCD

8 🗆 Myelodysplastic

Syndrome \rightarrow

21. Indicate the patient's disease using the disease definitions in the TCD Protocol, section 2.2.1. MSDISEAS 1
Refractory Anemia 2 C Refractory Anemia with Ringed Sideroblasts 3
Refractory Anemia with Excess Blasts 4 🗆 Refractory Anemia with Excess Blasts in Transformation 5 Chronic Myelomonocytic Leukemia

Continue with question 25

Non-Hodakins 9

9 [22. Is the patient beyond first complete remission? NHL1CR 1 🗆 Yes 2 🗆 No
4		23. Was the patient a primary induction failure?
		24. Have tumors demonstrated chemosensitivity defined as 50% reduction in mass size?NHLCHEMO1 □ Yes 2 □ No
		Continue with question 25
25.	Has the patient sign	ed the informed consent form? CONSENT 1 🗆 Yes 2 🗆 No
Pat	ient Clinical Status	
26.	Does the primary dis	sease include active CNS or skin leukemic involvement?CNS 1 🗆 Yes 2 🗆 No
27.	Does the patient req	uire additional mediastinal iradiation? MEDIAXRT 1 🗆 Yes 2 🗆 No
28.		preclude this patient from receiving complete total body irradiation PRIORXRT 1 Yes 2 No
29.	What is the patient's	Karnofsky (Lansky for patients <16 years old) performance status?
30.	Does the patient hav	ve an uncontrolled viral, bacterial or fungal infection?
31.	Is the patient HIV se	ropositive?
32.	Does the patient hav	e symptomatic cardiac disease?
		33. Record the left ventricular ejection fraction at rest ESFRACT
	2 □ No ↓	34. Does the ejection fraction improve with exercise? IMPROVE 1 I Yes 2 I No
		Continue with question 35
35.	Does the patient hav	e any pulmonary disease symptoms?
	$\begin{array}{c} PULMON \\ 1 \square \text{ Yes } \rightarrow \end{array}$	36. Record the DLCO (Diffusion capacity) DLCO
	2 🗆 No	of predicted (corrected
	↓ Continue with question 37	for whole blood hemoglobin) Continue with question 37

37. Provide the most recent values for the for		LLN
	ULN for your institution	for your institution
	mg/dL	
SGOT SCOT		OTULN
Total Serum BILI	mg/dL	
Bilirubin		. · · ·
38. Is the serum creatinine level \leq the institu	ution's ULN?	
$1 \square \text{Yes} \longrightarrow \text{Continue with question}$	40	[][]
2 □ No → 39. Record creatinine	clearance CRCLR	ml/min/1.73m ²
CRNORM	THODYNT	
40. Record the proposed starting date for co	onditioning therapy	
Patient HLA Data		
41. What are the patient's HLA-A and HLA-B	B phenotypes determined by serology?	
1	2	No. of Antigens Provided
	THLAA1 PATHLAA	▲ 1 □ One 2 □ Two
HLA-B	THLAB1 PATHLAB	
42. What is the patient's HLA-DRB1 genotyp	pe determined by high resolution DNA typi	
	MLADI PATHLAD	3 PATDN 0 1 One 2 Two
/	STHLADZ	
Unrelated-Donor HLA Data		
43. What are the unrelated donor's HLA-A a	nd HLA-B phenotypes determined by service	ology?
1	2	No. of Antigens Provided
		² 1 □ One 2 □ Two
HLA-B	RHLAB1 DNRHLAG	321 One 2 Two
44. What is the donor's HLA-DRB1 genotype	es determined by high resolution DNA typi	ng?
	RHLADA	DNRDNO
	/ DORHL	
		an een anti.
Comments:		
Signature	TCD Certification No.	Date

TCD	
T Cell Depletion	Trial

IMMUNOPHENOTYPING -GRAFT EVALUATION FORM

1 m		interfection in the state of the local distance
1	~	_ 7
1	1.01	· /
	UCL	-
6		

	Recipient NMDP ID:	
MCC Use Only Date Rcvd.:	TCD Name Code:	
ASSAYMAT	Center Code:	
	ion Sample 2 🗆 T10B9 Depleted 3 🗆 Rotor-off Fra	· ·
1. Record total number of nucleate	NUCLTOT	$ \square \square \bullet \square \mathbf{X} 2 \square 10^{9} $
2. Record total number of debris-fr	ree events acquired DFEVEN	
3. Was an anti-CD45 third stain us		
1	nti-CD45 stain 1 🗆 PerCP 2 🗆 PE-Cy5 🤋 🗆	Other, specify
$2 \Box No \qquad \downarrow \qquad $	CD45EVNM tal number of CD45+ events (from question 8-Tube 3) Continue with question 7.	
	events from a CD45 or CD45/CD14 stain . CD45C events in a CD45+ gate set on CD45 fluorescence	
	n the lymphocyte gate	

- 8. Record % of cells per quadrant in the lymphocyte gate (to one decimal place).

	FITC Stain	PE Stain	Isotype	FITC+/PE-	FITC-/PE+	FITC+/PE+
1	lgG1	lgG2		C1G2F	G1G2P	C1CZFP
2	lgG2	lgG1		G261F	GZG1P	G2G1FP
3	Anti-CD14	Anti-CD34	C14C34TS 1 □ G1/G2 2 □ G2/G1 3 □ G1/G1			
4	Anti-CD45Ra	Anti-CD4	୧୯୨୦୯୮୨ 1	CHSCHE	CHSCHP	C45C4FP
5	Anti-CD8	Anti-CD3	CBC3IS 1 □ G1/G2 2 □ G2/G1 3 □ G1/G1	C8C3F	CSC3P	C8C3 FP
6	Anti-CD3	Anti-CD16 + Anti-CD56	C16C56TS 1	C16C56F	CIGCSGP	C16C56FP
7	Anti-CD3+CD5	Anti-CD19.	C3C19 IS 1	C3C19F	C3C19P	C3C19FP
8	Anti-Tcr γδ	Anti-CD3 '	TC/C3 IS 1 □ G1/G2 2 □ G2/G1 3 □ G1/G1	TCR3F	TCRSP	TCRSEP
9	Anti-Tcr $\alpha\beta$.	Anti-CD5 '	$\begin{array}{c} T \subset \mathcal{R} \mathrel{\stackrel{\frown}{=}} \scriptstyle 1 \\ 1 \square G1/G2 \ 2 \square G2/G1 \ 3 \square G1/G1 \\ 4 \square G2/G2 \end{array}$	tCR5F	TCRSP	TCRSFP
	lgG1	lgG1	Record optional control, if used.	G1G10CF	G1G10CP	C1G10CFP

CD3PCT

 Record % PE-stained cells versus side scatter [using CD45(+) gate only] for 3-color analysis OR total debris-free events for 2-color analysis:

IgG1 PE (from question 8-Tube 2) IGG1PE

CD34(+) PE fluorescence (from question 8-Tube 3) .CD34PE ...

- 10. Record % CD3+ in infused marrow or in pre-depletion sample (based on question 8-Tube 5) ...
- 11. For panel using 7-AAD (OPTIONAL):
 - a. Record number of debris-free and 7-AAD-negative events acquired (for Tube 2 below)
 - b. Record total number of events in the lymphocyte gate (for Tube 2 below) GETALYMG
 - c. Record % of cells per quadrant in the lymphocyte gate (to one decimal place). (Elutriation centers must only complete Tubes 1-2 and T10B9 centers must complete Tubes 1-3.)

	FITC Stain	PE Stain	lsotype	FITC+/PE-	FITC-/PE+	FITC+/PE+
1	lgG1	lgG1		GETATGE	GE7 AIAP	GETAIGFP
2	Anti-CD45	Anti-CD3	1 - G1/G1 2 - Other GE7AACIS	GETAACF	GE7DACP	GEMAACEP
3	Anti-Tcr γδ	Anti-CD3	1 - G1/G1 2 - Other GETAATIS	CE7AATF	GETAATP	GE7AATTP

12. For pre-depletion samples:

Complete the information below for a sample of the LDA pre-depletion assay (i.e., harvested marrow after Ficoll Hypaque enrichment of the mononuclear cells).

a. Record # of debris-free events gated	GEPDDBFR	
b. Record # of lymphocyte events gated	GEDDINMG	

c. Complete the mini-panel below. (For 2-color analysis, complete Tubes 1-5. For 3-color analysis, complete Tubes 1-3.)

	FITC Stain	PE Stain	Isotype	FITC+/PE-	FITC-/PE+	FITC+/PE+
1	lgG1	lgG1		PDA161 PM	PDCIGIMP	PDG1G1PP
2	Anti-CD8	Anti-CD3		PDC8C3PM	PDC8C3MP	PDC8C3PP
3	Anti-Tcr γδ	Anti-CD3		P DTCC3PM	PDTCC3MP	PDTCC3PP
4	lgG1	lgG2		PDG1G2PM	PDG1G2MP	PDG1G2PP
5	Anti-CD45	Anti-CD14	1 0 G1/G1 2 0 G1/G2 PD4515 IS	PD4514PM	PDUSAUMP	PD4514PP

TCD

For rotor-off fraction reporting ONLY, complete the following:

13. Record the total number of nucleated cells, %CD3 and %CD34 cells **INFUSED** for each of the following fractions. Record 0 for Total Nucleated Cells Infused if no cells from that fraction were infused.

	Total Nucleated		
	Cells Infused	%CD3	%CD34
	F140CINE F140UNIT	F140CD3	F140034
140 Fraction			
CD34- Fraction	FC34CINF FC34UNIT		FC34CD34
Other, specify:	$ \begin{array}{c c} FOT1CINF & FOT1UNT \\ 1 & 10^{\circ} \\ 2 & 10^{\circ} \end{array} $		
Other, specify:	FOTZCENF FOTZUNI $\square \square $	Fot2cD3	Fot2CD34
14. Record analyzer's TCD laboratory certific	cation number	LABCERT	
Results reviewed by:		Date:	•
Comments:			

After the form has been completed and reviewed in the laboratory, give the form to the TCD Clinic Coordinator for signature and submission to the Medical Coordinating Center.

Signature

Top		GVHD
T Cell Depletion Trial	ACUTE GVHD WEEKLY AS	SESSMENT FORM
MCC Use Only Date Rcvd.:	Recipient NMDP ID: TCD Name Code: Center Code: Assessment Number:	
1. Date of staging	STACEDT	M D Y
2. Record cyclosporine trough leve		$g/mL \square \square \square \square \square \square$
	n abnormalities during the assessment period Maculopapular 3 Maculopapular rash < 25% rash, 25-50% of of body surface body surface	Generalized 5 Generalized ery- erythroderma throderma with bullous formation and desquamation
0 🗌 No diarrhea	adult patients and mL/m² for pediatric patients □ Diarrhea > 500 3 □ Diarrhea > 1000 but ≤ 1000 mL/day but ≤ 1500 mL/day or or 280-555 mL/m² 556-833 mL/m²	 5) 4 □ Diarrhea 5 □ Severe abdominal pain > 1500 mL/day or > 833 mL/m² blood or melena
Liver 1 🗆 Bilirubin 2 🗌 ORGABLVR < 2.0 mg/dl	Bilirubin 3 ☐ Bilirubin 2.0-3.0 mg/dl 3.1-6.0 mg/dl	4 🗌 Bilirubin 5 🔲 Bilirubin 6.1-15.0 mg/dl > 15.0 mg/dl
Upper GI 1 D No protracted ORGABUGE nausea and vomitin	2 🗌 Persistent nausea, vomiti g	ng or anorexia
	gietnics vo I No symptoms giet tpn gietgyndi I GVHD 4 I TPN gietgyndi I GVHD 5 Infection.	C Drug Reaction 6 □ VOD ivet rol
5. Record biopsy results pertaining BIOSK N 1 Positive 3 Equivocal 2 Negative 4 Not Done	to GVHD for this assessment period: Intestinal Tract (upper or lower) 1 Positive 3 Equivocal 2 Negative 4 Not Done	I I Positive 3 I Equivocal 2 I Negative 4 I Not Done
6. Was primary or secondary treatment	nent for GVHD initiated? $RXIN$	⊥ ,
Comments:		

Signature

TCD Certification No.

Date

THE RULE OF NINES





То	HEMATOPOIE	SIS ASSESSMENT	FORM HEMATOP	T
T Cell Depletion Trial		Recipient NMDP ID:		
MCC Use Only		TCD Name Code:		
Date Rcvd.:		Center Code:		
ASSES	SSPD 1 □ Day 28 Post-BMT	2 🗆 Day 100 Post-B	MT 3 🗆 Secondary Graft	Failure
1 Did the patient engraft	as evidenced by an ANC	$2 \ge 500/\text{mm}^3$ on 3 consecutiv	ve days?	
ENGRAFT	2. Record ANC values			
2 🗆 No]/mm3 ANC1 ANC1		
3 □ Previously reported ↓]/mm3 ANCZ ANCZ	<u>я</u> П П Г	Т Ч
		/mm3 ANC3 ANC		Y Y Y
		Continue with ques	stion 3	
 3. Did the patient have se <i>TMPNEUT</i> 1 □ Yes → 2 □ No 	4. Record % of marrov	< 500/mm ³) without subsequences of the subse	1 11]%
6. Record chimerism assa		r blood.	Assay Results	+
Marrow BMCH		Primary Method Use codes below.	BMCH MRES 1	
□ Marrow chimerism not o			$3 \square$ Host and donor $\rightarrow \square$	% donor
Blood BLCHM		If Other, specify:	2 LI All donor cells	FDN R
			Polymerase chain reaction (PCR)	
Primary method codes:	 Standard cytogenetics Fluorescent in situ hybri Restriction fragment-len 	idization (FISH) 5 ·	- HLA serotyping - Other	
 7. Did the patient receive STEMCELL 1 □ Yes → 2 □ No 	stem cell reinfusion (mar 8. Record date of infus	- a mar in the second	to inadequate hematopoietic fu	nction?
Comments:				
Signature	T	CD Certification No.	Date	

, and sur-

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		MISSION FORM	NOSPIT	TAL)
T Cell Depletion Trial	nc-Au		4 C Sector Sector Company (1999)	
MCC Use Only Date Rcvd.:	HOSPDT	Recipient NMDP ID: TCD Name Code: Center Code: Date of Re-Admission	n: M	
1. Date of Discharge		DISCRADT	ПС	
2. Patient status at discharge If 2-Dead, complete Death Form	n.	PATSTAT	•••••	1 🗆 Alive 2 🗆 Dead
3. Record the primary reason for I	nospitalization and	indicate if the other cate	egories contributed	or not.
	Record	only 1 primary reason.		
GVHD	NGVHD	1 🗆 Primary	2 🗆 Contributing	3 🗆 Non-contributing
RelapseRSN	VRLPS	1 🗆 Primary	2 🗌 Contributing	3 🗆 Non-contributing
Graft Failure	N NGF	1 🗆 Primary	2 🗆 Contributing	3 🗆 Non-contributing
InfectionR.	SNINE	1 🗆 Primary	2 Contributing	3 🗆 Non-contributing
OtherR. Specify: <u>HSPTEXT</u>			2 🗆 Contributing	3 🗆 Non-contributing
 Record the number of days on Comments:				<u> </u>
,				

.

			INFECT	
TCell Depletion Trial	POST-TRAN	SPLANT INFECTIO	ON FORM	
MCC Use Only Date Rcvd.:	/	Recipient NMDP ID TCD Name Code: Center Code:):	
1. Starting date of infect	ion episode/visit date co	<i>INFEC</i> onfirming an infection-free p	1 11	
2. Does this form docun	nent an infection episode	\downarrow	Yes 2 \Box No \longrightarrow Si ith question 3	gn and submit the form
3. Record all clinically in	nportant infections prese	ent. Site	Organism	Severity Scale
Bacteria	$\begin{array}{c} BACINF \\ 1 \square Yes \rightarrow \\ 2 \square No \\ \downarrow \end{array}$		BACORG1 BACORG2 TNETEXT/BAC	□ BAC5EV1 □ BAC5EV2 15P = BAC25P
Fungal	$FNGINF$ 1 \Box Yes \rightarrow 2 \Box No \downarrow	FNGSIT1	F F F	NGORG1 FNGSEV1 NGORG2 FNGSEV2
Viral	VIRINF 1 \Box Yes \rightarrow 2 \Box No \downarrow	VIRSITA		CRORAL VERSEV1
Protozoa	PROENF 1 \Box Yes \rightarrow 2 \Box No	If Other, specify:	P	CRISPAVER28P 2008G1 PROSEV1 2008G2 PROSEV2
Other	$\downarrow \qquad \qquad$	OTHSITI		15P& PRO2SP THORG1 OTHSEV1 HORG2 OTHSEV2 V1SPQ OTH2SP
		If Other, specify: <u>I</u>	WFIERI / OTT	A Pol A PLUE AL

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4. Was the only diagnosis for this episode "Fever of Undetermined Origin"? 1 D Yes 2 🗆 No

Sign and submit the form

Common Sites of Infection

Gentio-Urinary Tract 01 Blood/Buffy Coat Disseminated - Generalized, 02 isolated at 3 or more distinct sites 24 Kidneys, Renal Pelvis, Ureters, and Bladder Prostate Central Nervous System 25 26 Testes 27 Fallopian Tubes, Uterus, Cervix 03 04 Brain Spinal Cord 28 Vagina Gentio-Urinary Tract unspecified 05 Meninges and CSF 29 06 Central Nervous System Skin unspecified Gastrointestinal Tract 30 Genital Area Cellulitis 31 Herpes Zoster 07 32 Lips Tongue, Oral Cavity, and Oro-33 Rash, Pustules, or Abscesses not 08 typical of any of the above Pharynx 09 Esophagus 34 Skin unspecified 10 Stomach Galibladder and Bilinary Tree (not Other 11 Hepatitis), Pancreas Central Venous Catheter, not 35 12 Small Intestine 13 Large Intestine otherwise specified Woundsite or Catheter Tip Feces/Stool 36 14 37 Eyes 15 Peritoneum Ears 38 16 Liver 17 Gastrointestinal Tract unspecified 39 Joints Bone Marrow 40 41 Bone Cortex (Osteomyelitis) **Respiratory Tract** 42 Muscle (excluding Cardiac) Upper Airway and Nasopharynx 43 Cardiac (Endocardium, 18 Laryngitis/Larynx Myocardium, Pericardium) 19 44 Lymph Nodes 20 21 22 Lower Respiratory Tract (lung) Spleen Pleural Cavity, Pleural Fluid 45 46 Other unspecified Sinuses 23 Respiratory Tract unspecified

Commonly Reported Organisms

Bacteria

Specific bacteria will not be identified for infections.

Fungal Infections

Asperguillus Niger Asperguillus, not otherwise specified Cryptococcus Species Fusarium Species Mucormycosis (Zygomycetes, Rhizopus) Yeast, not otherwise specified Other Fungus
specified Cryptococcus Species Fusarium Species Mucormycosis (Zygomycetes, Rhizopus) Yeast, not otherwise specified
Cryptococcus Species Fusarium Species Mucormycosis (Zygomycetes, Rhizopus) Yeast, not otherwise specified
Fusarium Species Mucormycosis (Zygomycetes, Rhizopus) Yeast, not otherwise specified
Mucormycosis (Zygomycetes, Rhizopus) Yeast, not otherwise specified
Rhizopus) Yeast, not otherwise specified
Yeast, not otherwise specified
Other Fungus
Influenza (Flu)
Measles (Rubeola)
Mumps
Papovavirus
Respiratory Syncytial Virus (RSV)
Rubella (German Measles)
Parainfluenza
HHV-6 (Human Herpes Virus)
Epstein-Barr Virus (EBV)
Polvomavirus
Rotavirus
Rhinovirus (Common Cold)
Other Viral
Amebiasis
Echinocoocalcyst
Trichomonas either vaginal or
gingivitis
CHILLIANS
Other Protozoal (Parasite)

01	Mycobacterium Tuberculosis	O4	Mycoplasma
02	Other Mycobacterium	O5	Other Organism
03	Legionella	O6	No Organism Identified

Severity Scale

- 1. Mild, no active treatment (e.g., viral syndromes)
- 2. Moderate, requires outpatient PO antibiotic
- 3. Severe, requires IV antibiotic or antifungal or hospitalization
- 4. Life-threatening (e.g., septic shock)
- 5. Caused or contributed to death

Comments:

IMMUNOPHENOTYPING - IMMUNE RECONSTITUTION FORM							
T	Cell Depletion Tr	ial		-			
			Recipient NMDP	id:			
Date	MCC Use e Rcvd.:	Only	TCD Name Code	:]
			Center Code:				٦
Evalu	Lation period:	IALPD	1 mon 2 🗆 3 mon 3 🗆 6 mon	4 🗆 12 mon	5 🗆 18 ma	on 6 □ 24 mc	- on
1. D	ate of blood draw	r	BLDRAWS	DT .			
				· · · · · · · · · · · · · · ·	M		
2. R	ecord sample WE	BC	NUCCELCT			WBCE 1 □ 10 ⁵ / X 2 □ 10 ⁹ /	χ. [[]
3. Re	ecord % of lymph	ocytes in the s	sample	RLYMDIF			%
4. Re	ecord total numbe	er of events in	the lymphocyte gate	1 EVENT]
	as a third stain us		AIN3 1 PerCP 2 PE-Cy5 9		· · · · · harrand harra	(()	L
6. Re	ecord % of cells		n the lymphocyte gate (to one decima				
[FITC Stain	PE Stain	Isotype	FITC+/PE-		T	ק
1	lgG1	lgG2a	isotype	G1F	GZP	FITC+/PE+	╢┈
2	lgG2a	lgG1		GZF	GIP	G1FG2P G2FG1P	╢
3	Anti-CD45	Anti-CD14	CUSC14IS 1 G1/G2a 2 G2a/G1 3 G1/G1	C45	C14	C45C14	┨┈┈
4	Anti-CD8	Anti-CD28	C8C28 IS 1 □ G1/G2a 2 □ G2a/G1 3 □ G1/G1	C8	C28	C8C28	
5	Anti-Tcr αβ	Anti-CD8	CABC8PIS 1 □ G1/G2a 2 □ G2a/G1 3 □ G1/G1	TAB	C8P	TABOSP	-
6	Anti-CD45Ra	Anti-CD4	C45RC4IS 1 🗆 G1/G2a 2 🗆 G2a/G1 3 🗆 G1/G1	C45R	C4	C45RC4	antes
7	Anti-CD16	Anti-CD56	C16C56 IS 1 □ G1/G2a 2 □ G2a/G1 3 □ G1/G1	C16	C56	C16C56	ero kuličije;
8	Anti-CD57	Anti-CD3	1 □ G1/G2a 2 □ G2a/G1 3 □ G1/G1 4 □ M/G1 CS7C3AIS	C57	C3A	C57C3A	
9	Anti-CD5	Anti-CD19	CSC19AIS 1 □ G1/G2a 2 □ G2a/G1 3 □ G1/G1	C5	C19A	CSC19A	
10	Anti-Tcr γδ	Anti-CD3	1 🗆 G1/G2a 2 🗋 G2a/G1 3 🗆 G1/G1	aD	C3B	GDC3B	
11	Anti-HLA DR	Anti-CD3	DRC3CIS 1 🗆 G1/G2a 2 🗆 G2a/G1 3 🗆 G1/G1	DR	C3C	DRC3C	
12	Anti-CD3	Anti-CD8	C3C8 15 1 □ G1/G2a 2 □ G2a/G1 3 □ G1/G1	CBD	C8B	C3DC8B	Carriegenerate
13	Anti-CD3	Anti-CD56	C3C5CIS 1 □ G1/G2a 2 □ G2a/G1 3 □ G1/G1	C3	C56B	CBCSLB	
	lgG1	lgG1	Record optional control, if used.	IGG1F	IGGIPA	IGGIGI	
	IgM	lgG1	Record optional control, if used.	IGMF	IGG1PB		

Question 7 continued on Page 2

TCD IMMUNE RECONSTITUT	ION FORM (Continued)	Recipient NMD			
7. Record analyzer's TCD laborato	ry certification number	LABC	ERT		
Results reviewed by:			Date	e:	
Comments					
		· .			
Signature, Lab Technologist	, ,			Date	
Signature	TCD Certificat	tion No.		Date	
	· · · · ·				

- Annar

Recipient NMDP ID:MCC Use OnlyTCD Name Code:Date Rovd.:Center Code:1MAL2ALL4Lympho-blastic24Lymphoma5Undiffer-entiatedBlood1YesBMBLS/N2NoBlood1YesPRTMDX3. Was disease detected at an extramedullary site?FXTMDX4. Lave host cells reappeared?6. Have host cells reappeared?7. Primary method:1Yes2No8. Have cytogenetic abnormalities reappeared?2No8. Have cytogenetic abnormalities first observed.4. Lave site observed.4. Date abnormalities first observed.5. Have cytogenetic abnormalities first observed.6. Have cytogenetic abnormalities first observed.9. Date abnormalities first observed.4. Date abnormalities first observed.	TCell Depletion Tria	RELAPSE FORM	RELAPSE
 1 □ AML 2 □ ALL → 4 □ Lympho- blastic Lymphoma 5 □ Undiffer- entiated Leukemia 6 □ Biphenotypic Leukemia 7 BMBLSYN 2 □ No 8 Blood 1 □ Yes → 9 □ 0 0 1 □ Yes → 1 □ Yes → 1 □ Yes → 2 □ No 8 □ No test 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	Date Rcvd.:	TCD Name Code: Center Code:	
A □ Lymphor- blastic Lymphoma S □ Undiffer- entiated Leukemia 6 □ Biphenotypic Leukemia 7 BBLSYN 2 □ No Blood 1 □ Yes → □ □ □ Leukemia 8 □ Biphenotypic Leukemia 9 BBLSYN 2 □ No 9 BBCT 9 BBLSDT 3. Was disease detected at an extramedullary site? FXTRAMED 1 □ Yes → 4. Date disease first detected 2 □ No 5. Was disease confirmed by pathology? 1 □ Yes 2 □ No Continue with question 6 PAT HCONF 6. Have host cells reappeared? ACHOST 1 □ Yes → 7. Primary method: 2 □ No 8 □ No test performed 4. Have cytogenetic abnormalities reappeared? CYTORBN 8. Have cytogenetic abnormalities reappeared? CYTORBN 8. Have cytogenetic abnormalities first observed . □ □ □ □ □ M □ Y	$1 \square AML$ $2 \square ALL \longrightarrow$	2. Were leukemic blasts documented in the marrow or	
 PRIMDX 3. Was disease detected at an extramedullary site? FMDISDT Yes → 4. Date disease first detected M D Y 2 □ No 5. Was disease confirmed by pathology? 1 □ Yes 2 □ No Continue with question 6 PAT HCONF 6. Have host cells reappeared? ACHOST 1 □ Yes → 7. Primary method: 1 □ Standard cytogenetics 2 □ FISH 3 □ RFLP 4 □ PCR 5 □ HLA serotyping 2 □ No 9 □ Other, specify: Continue with question 8 performed 8. Have cytogenetic abnormalities reappeared? CYTOABN ABNORMDT 1 □ Yes → 9. Date abnormalities first observed . M D Y 	blastic Lymphoma 5 🗆 Undiffer- entiated Leukemia 6 🗆 Biphenotypic	$\begin{array}{c ccccccccccccccccccccccccccccccccccc$	$\begin{bmatrix} \square & \square & \square & \square \\ T & M & B & L & S \\ \square & \square & \square & \square & \square \\ T & M & D & Y \end{bmatrix}$
 6. Have host cells reappeared? ACHOST 1 □ Yes → 7. Primary method: 2 □ No 2 □ No 8 □ No test 9 □ Other, specify: Continue with question 8 Performed 4 8. Have cytogenetic abnormalities reappeared? CYTOABN ABNORMDT 1 □ Yes → 9. Date abnormalities first observed 	PRIMDX	 EXTRAMED 1 □ Yes → 4. Date disease first detected 2 □ No 5. Was disease confirmed by path 	EM DISDT
1 \Box Yes \rightarrow 9. Date abnormalities first observed . \square \square \square \square \square \square \square \square Y	· ·	1 \Box Yes \rightarrow 7. Primary method: 1 \Box Sta 3 \Box RFI 2 \Box No 9 \Box Oth 8 \Box No test	METN ndard cytogenetics 2
2 □ NO 3 □ N/A 8 □ No test performed <i>Continue with question 28</i>		 1 □ Yes → 9. Date abnormalities first observe 2 □ No 3 □ N/A 8 □ No test performed 	d. M D Y

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TCD

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7 🗆 Juvenile	10. Does patient have leukocytosis? LEUKOYN 1 DYes 2 DNo
$CML \rightarrow$	11. Record absolute monocytes ABMONOCY
	12. Have immature myeloid cells been detected in the peripheral blood?
	1 □ Yes → 13. Record dates of two consecutive marrow specimens indicating
	2 □ No the presence of immature myeloid cells.
ન	IMATMYEL Date of 1st specimen Image:
	IMMYSIDT M D Y
	Date of 2nd specimen LL LL LL
	Continue with question 28
$_3 \Box CML \rightarrow$	14. Have immature hematopoietic cells been documented in the peripheral blood?
	1 \Box Yes \rightarrow 15. Date first documented
	2 DNO IMMATHEM IMMHEMDT Y
	16. Has myeloid hyperplasia in the bone marrow been documented (in the absence of
	infection or growth factor therapy)?
	1 \Box Yes \rightarrow 17. Date first documented
	2 DNO MYELHYPR MYELWYDT
	18. Have host cells reappeared?CMLHOST
	1 \Box Yes \rightarrow 19. Primary method: 1 \Box Standard cytogenetics 2 \Box FISH
	3 🗆 RFLP 4 🗆 PCR 5 🗆 HLA serotyping
	2 🗆 No 9 🗆 Other, specify:
	8 No test CMLMETH Continue with question 20 performed
、	
	\mathbb{Y}
	20. Has the 9;22 translocation reappeared? 1 \Box Yes \rightarrow Continue with question 21
	$T922 \ \ \ 2 \square \ No \ \ \rightarrow \ Continue \ with \ question \ 28$
	$3 \square N/A \rightarrow Continue with question 28$
	21. Record date of cytogenetic analysis .C.YT.D.D.T
	M D Y
	22. Record number of metaphases analyzed
	23. Record number of metaphases exhibiting 9;22 translocation METATRN
	Go to question 28 if the number of metaphases analyzed ≥ 10
	and > 50% exhibit the 9;22 translocation
	24. Record date of second cytogenetic analysis
	25. Record number of metaphases exhibiting 9;22 translocation .METATRN2
	Continue with question 28

8 🗆 MDS 🛛 –

TCD

\rightarrow	26. Have MDS-associated morphologic abnormalities reappeared?						
	1 \square Yes \rightarrow 27. Record dates of two consecutive marrow specimens and % cells 2 \square No of host origin.						
	2 I No of host origin. MDSABNYN MDSS1DT Date of 1st specimen Image: Constant of the specimen constant of the						
	Date of 1st specimen L						
	% cells host origin HOSTORG1						
	MDSS2DT Date of 2nd specimen						
	% cells host origin HOSTOR 6.2						
	Continue with question 28						

28. Have the following therapies been initiated for relapse reversal?

Infusion of donor lymphocytes	$_1$ \Box Yes \rightarrow	DRINFD7 Date first performed			
DNRINFUS	2 🗆 No		M	D	Y
Interferon use	1 \Box Yes \rightarrow	INTERFDT Date first performed			
INTERFER	2 🗆 No	SCHOTYNT			Y
Second transplant	1 \Box Yes \rightarrow	SCNDTXDT Date first performed			
	2 🗆 No	OTN RRXDT			
Other, specify: OTHERRY -	, 1 \Box Yes \rightarrow	Date first performed			
·	2 🗆 No		**	5	1

Signature

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TCell Depletion Trial	SUPPORT MEASURES FORM	SUPPORT
MCC Use On Date Rcvd.:	Ily TCD Name Code: Center Code:	
TIMEPD	21 post-BMT 2 Day 22 post-BMT to initial discharge	3 Initial discharge to 6 mon
Ail data should	DASTOTOT	
2. End of assessment	period	M D Y
3. Record the number	of days the patient received hyperalimentation HYPER	
4. Record the number Include number of c	of days the patient received IV antibiotics (other than gancicle days patient received IV antifungal agents.	lovir and foscarnet)
5. Record the number	of units of red blood cells transfused $\dots \mathcal{RB}$	с.т.х
6. Did the patient recein PLTLTTX 1 □ Yes → 2 □ No Continue with Question 10	 a platelet transfusion(s)? 7. Record the number of random donor platelet units 8. Record the number of HLA-matched single donor units 9. Record the number of single donor units (not HLA matched continue with question 10) 	MTCHUNIT
10. Record the number	r of outpatient clinic and home care visits	PATCL
11. Record the number	r of days on a ventilator	NTDAYS
12. Record the numbe	r of days in hospital requiring intensive nursing support \ldots \beth	NSDAYS
Signature	TCD Certification No.	Date

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T Cell Depl	letion Trial			TOXIC	
			Recipient NMDP ID:		
	C Use Only		TCD Name Code:		
Date Rovd.:			Center Code:		
. Date of	evaluation	· · · · · · · · · · · · · · · · · · ·	EVALDT	ПП Г	
	he highest grade of the second s	of toxicity diagnosed by	the day of evaluation.	Use the grading scale o	n the back of p
	Grade 0	Grade I	Grade II	Grade III	Grade IV
ardiac GCARD	0 🗌 No EKG abnormality	1 D Mild EKG abnormality	2 D Moderate EKG abnormality	3 Severe EKG abnormality	4 🛛 Fatal toxicity
adder BLAD	o 🗋 None	 Macro. hem. 2d. from last chemo 	 2 Macro. hem. 7d. after last chemo 	3 🛛 Hem. cystitis with frank blood	4 🛛 Fatal toxicity
enal RENL	o 🗌 None	1 Creat. increase up to 2 x baseline	2 Creat. above 2 x baseline	з 🗌 Dialysis required	4 🛛 Fatal toxicity
Ilmonary PULM	o 🗆 None	1 □ See scale	2 🗋 See scale	3 🗆 See scale	4 🗆 Fatal toxicity
epatic HEPT	o 🗆 None	1 🛛 Mild hep. dysfunction	2 🗌 Mod. hep. dysfunction	3 🗆 Severe hep. dysfunction	4 🗆 Fatal toxicity
is CNS	o 🗋 None	1 Somnolence + arousable	2 Somnolence + confusion	3 🗆 Seizures or coma	4 🛛 Fatal toxicity
omatitis	o 🗌 None	1 □ Pain and/or ulceration, no IV narc. drug	2 Pain and/or ulceration with IV narc. drug	 3 Severe ulcer. and/or mucositis see scale 	4 🗌 Fatal toxicity
Toxicity	0 🗌 None	1 ☐ Watery stools >500 mL but <2,000 mL every o	2 🗌 Watery stools >2,000 mL d. every d.	3 🗆 lleus require nasogastric suction	4 🛛 Fatal toxicity
Did the p	atient have an alle	1 🗆 Broncho	spasm, no 2 al therapy needed	2 🗆 Anaphylaxis	

e 1	🗆 Nausea
-----	----------

з П Vomiting requiring therapy

If patient received Methotrexate for GVHD prophylaxis post-transplant, complete question 5. If no Methotrexate prophylaxis was given, sign and submit the form.

5. Record Methotrexate dosing for GVHD prophylaxis.

	Day 1	Day 3	Day 6	Day 11
	METHDIDT	METHOJDT	METHOGOT	METH11DT
Date	M D Y	M D Y	M D Y	M D Y
· · · · · · · · · · · · · · · · · · ·	MEHDITD	METHD3TD	METH DGTD	METH11TD
Total Dose (mg)	• mg	ـــــا • اــــــا mg	ـــــا • ـــــا mg	└」● └」 mg
Full Dose Given?	METH D1 FD 1 □ Yes 2 □ No ↓	METH D3ED 1 □ Yes 2 □ No ↓	METHD6 FD 1 □ Yes 2 □ No ↓	METH 11 FD 1 □ Yes 2 □ No ↓
Reason(s) for Reducing/ Withholding Dose			х	
Renal Dysfunction Mucosal Toxicity Fluid Accumulation Liver Dysfunction Other	$1 \square Yes 2 \square No$ $4 \square Yes 2 \square No$	$1 \square Yes 2 \square No$	1 □ Yes 2 □ No 1 □ Yes 2 □ No ↓	1 □ Yes 2 □ No 1 □ Yes 2 □ No ↓
	Specify:	Specify:	Specify:	Specify:
Comments:				
	METHD1MT METHD1FA METHD1LD	METHD3MT METHD3FA METHD3LD	METH DG MT METH DGFA METH DGLD	METH11RD METH11MT METH11FA METH114FA METH114LD METH110T

Signature

TCD Certification No.

Date

TOXICITY GRADING SCALE

	GRADE I	GRADE II	GRADE III
Cardiac toxicity	Mild EKG abnormality, not requiring medical intervention; or noted heart enlargement on CXR with no clinical symptoms	Moderate EKG abnormalities requiring and responding to medical intervention; or requiring continuous monitoring without treatment; or congestive heart failure responsive to digitals or diuretics	Severe EKG abnormalities with no or only partial response to medical intervention; or heart failure with no or only minor response to medical intervention; or decrease in voltage by more than 50%
Bladder toxicity	Macroscopic hematuria after 2 d from last chemotherapy dose with no subjective symptoms of cystitis and not caused by infection	Macroscopic hematuria after 7 d from last chemotherapy dose not caused by infection; or hematuria after 2 d with subjective symptoms of cystitis not caused by infection	Hemorrhagic cystitis with frank blood, necessitating invasive local intervention with installation of sclerosing agents, nephrostomy or other surgical procedure
Renal toxicity	Increase in creatinine up to twice the baseline value (usually the last recorded before start of conditioning)	Increase in creatinine above twice baseline but not requiring dialysis	Requirement of dialysis
Pulmonary toxicity	Dyspnea without CXR changes not caused by infection or congestive heart failure; or CXR showing isolated infiltrate or mild interstitial changes without symptoms not caused by infection or congestive heart failure	CXR with extensive localized infiltrate or moderate interstitial changes combined with dyspnea and not caused by infection or CHF, or decrease of PO_2 (> 10% from baseline but not requiring mechanical ventilation or > 50% O_2 on mask and not caused by infection or CHF	Interstitial changes requiring mechanical ventilatory support or > 50% oxygen on mask and not caused by infection or CHF
Hepatic toxicity	Mild hepatic dysfunction with 2.0 mg% \leq bilirubin \leq 6.0 mg%; or weight gain > 2.5% and $<$ 5% form baseline, of noncardiac origin; or SGOT increase more than 2-fold but less than 5-fold from lowest pre-conditioning	Moderate hepatic dysfunction bilirubin > 6 mg% < 20 mg%, or SGOT increase > 5-fold from pre- conditioning; or clinical escites or image documented escites > 100mL; or weight gain > 5% from baseline of noncardiac origin	Severe hepatic dysfunction with bilirubin > 20mg%; or hepatic encephalopathy; or ascites compromising respiratory function
CNS toxicity	Somnolence but the patient is easily arousable and oriented after arousal	Somnolence with confusion after arousal; or other new objectives CNS symptoms with no loss of consciousness not more easily explained by other medication, bleeding, or CNS infection	Seizures or coma not explained (documented) by other medication, CNS infection, or bleeding
Stomatitis	Pain and/or ulceration not requir- ing a continuous IV narcotic drug	Pain and/or ulceration requiring a continuous IV narcotic drug (morphine drip)	Severe ulceration and/or mucositis requiring preventive intubation; or resulting in documented aspiration pneumonia with or without intubation
GI toxicity	Watery stools > 500 ml but < 2,000 mL every d not related to infection	Watery stools > 2,000 ml every d not related to infection, or macroscopic hemorrhagic stools with no affect on cardiovascular status not caused by infection; or subileus not related to infection	Ileus requiring nasogastric suction and/or surgery and not related to infection; or hemorrhagic enterocolitis affecting cardiovascular status and requiring transfusion

Note: Grade IV regimen-related toxicity is defined as fatal toxicity.

Abbreviations: CXR, chest x-ray, IV, intravenous

Reference: Bearman SI, Appelbaum FR, Bucker CD, Peterson FB, Fisher LD, Clift RA, Thomas ED. (1988). Regimen-related toxicity in patients undergoing bone marrow transplantation. *Journal of Clinical Oncology* 6(10):1562-1568.

TCD	
T Cell Depletion	Tria

Date Rcvd.:

MCC Use Only

HQL BASELINE INTERVIEW

Recipient NMDP ID:	
 TCD Name Code:	
 Center Code:	

Good Morning/Afternoon/Evening, this is Joan Shepherd calling from The University of Iowa. Is this **/name**? I am calling to talk with you about how things have been going for you in the last few weeks. This is the telephone call that **/nurse** coordinator told you we would have at this time.

Is this a good time for you? (If no) What might be a better time--later tonight or tomorrow evening?

During this phone call, I'm going to talk with you about how your work, your everyday life around your home, your family, and your social relationships have been affected by your illness. It is important that you answer each question as best you can. We're asking these questions of patients all over the country, and your answers will be combined with theirs to give us a picture of how you are doing as a group. Your answers will be confidential. If you don't understand any question, please let me know and I will explain it to you. Also, you will answer some of the questions using the colored sheets of paper that I sent to you. Do you have those with you now?

As we go through the interview, you will notice that many of the questions are answered with a number. Take out the **white** sheet of paper now. Suppose I asked you how much you like chocolate, and you are to answer using the top answer key. Your answer could be anywhere from 0, which means "not at all," to 4, which means "very much." What would your answer be? (Clarify.)

I want to remind you that this is a voluntary study and you have the right to refuse to answer any question or any set of questions that you choose. We believe, however, that you as well as others will benefit from discussing your problems and concerns as a transplant patient.

Let's begin.

How long did it take to complete the interview?

hours minutes

Where was the interview conducted?

- (1) At the patient's home
- (2) In a hotel or motel
- (3) At a Ronald McDonald House
- (4) In the hospital
- (9) Other, specify: _

TCD: HQL ASSESSMENTS

	(# of items)	Baseline	100 Days	6 Months	1 Year	3 Years
	i		•			
Functional Assessment of Cancer T (FACT)	herapy (47)	Х	Х	X	Х	X
Medical Outcomes Study Short For (MOS SF36)	m 36 (36)	X			Х	Х
Bush BMT Module	(57)	Х	X	X	Х	X
Perceived Health Questionnaire (PHQ)	(4)	Х	X	X	X	X
Occupational Functioning Items	(6)	Х		X	X	X
Sexual Functioning Items	(43)	Х		X	Х	X
Centers for Epidemiological Studie Depression (CES-D)	s of (20)	X	X	X	X	X
Bradburn Affect Balance Scale	(10)	Х	X	X	Х	Х
Ladder of Life	(3)	Х	Х	X	X	Х
Social Support Rand Medical Outco (MOS)	omes Study (20)	Х			Х	· · · · ·
Berkman & Syme Social Network I (SNI)	ndex (4)	X	<u></u>		Х	·
Cancer Behavior Inventory: Self-eff (CBI)	ficacy (14)	Х				
Life Orientation Test (LOT)	(13)	X				
Coping Orientations to Problems Encountered (COPE) (30)	Dispositional	X				
	Situational			X		

Methods for Scoring HQL Instruments

Scoring the FACT BMT

The FACT-BMT measures health-related functioning that is specific to the disease and treatment under study. The general portion of the FACT, the FACT-G, is designed to evaluate the HQL of patients receiving cancer treatment. It is comprised of five subscales that measure the following key aspects of HQL: Physical Well-being, Social/family Well-being, Relationship with Doctor, Emotional Well-being, and Functional (role) Well-being. An additional subscale of 12 items was specifically developed for use in bone marrow transplant patients with disease and treatment specific questions. The FACT-BMT is the primary endpoint for the TCD HQL substudy, and is administered with every interview.

The scoring of the FACT BMT was conducted using the FACT Manual Version 4. The TCD instrument is version 3 of the FACT-BMT, and is scored differently from version 4 in two respects. First, the Relationship with Doctor domain is scored in version 3 but not in version 4. Secondly, the sixth item of the Emotional Well-Being domain "I worry that my condition will get worse" is scored in version 4, but not in version 3. To facilitate comparison with published norms for version 3 of the FACT-BMT, we have chosen to omit this item from the scoring. We also omit two of the BMT subscale items "I have concerns about my ability to have children" and "I regret making the decision to have a bone marrow transplant" as these items were omitted in the analysis that validated the FACT (McQuellon RP et. al. (1997)).

In contrast to previous analyses of the FACT presented to the DSMB, the scoring of the FACT in this analysis is restricted to completed interviews, and does not impute missing values for the FACT. In previous analyses, patients who died before an interview were scored as 0. In addition, interviews missing for other reasons were scored as 2.5, which is equivalent to scoring each domain as 0.5. This policy of imputation was in accord with the T cell depletion protocol, but sometimes obscured the fact that apparent treatment differences in HQL scores are attributable to differences in morbidity and mortality.

To facilitate analysis of the FACT as an HQL outcome measure, it is desirable to reduce the dimensionality of the instrument. Several aggregate scores for the FACT-BMT are presented in the scoring manual and validated in previous studies. The version 3 FACT-G Total adds up 26 items from the five general domains plus 2 items comprising "Relationship with Doctor". With the addition of the 10 FACT-BMT Concerns specific to the Bone Marrow Module, the 38 item FACT-BMT total is obtained. As recommended by Dr. David Cella, we also compute the 24 item FACT-BMT Trial Outcome Index (FACT-TOI), which aggregates the Physical and Functional Well-Being and the FACT-BMT Concerns domains.

For analysis purposes, we consider the FACT-TOI, and two additional aggregates constructed by the TCD statistical staff, the FACT-MCS and the FACT-PCS. These latter measures were motivated by the SF-36 Mental and Physical Component scores. The FACT-MCS is the aggregate of the Emotional and Social Well-Being domains, and the FACT-PCS is the aggregate of the Physical and Functional Well-Being domains. Both the FACT-MCS and the FACT-PCS are rescaled to range from 0 to 100, to make them more comparable to their SF-36 counterparts. The FACT-TOI, which is the aggregate of 24 items scored 0-4, has a raw range of 0 to 96, is not rescaled.

Scoring the MOS SF-36

The MOS SF-36 measures health concepts that represent basic components of functioning that underlie health status and well-being irrespective of disease and treatment. The eight components of the SF-36 are Physical Functioning, Role Physical, Pain Index, General Health Perceptions, Vitality, Social Functioning, Role Emotional, and Mental Health Index. Each domain is positively scored indicating that higher scores are associated with positive outcome. This scale has been widely applied in a variety of outcome studies and is being used in this Trial as a generic measure of quality of life. The instrument is administered at baseline, and one and three years post-transplant for all adult patients.

The scoring of the MOS SF-36 was conducted using the software provided with the manual "Scoring Exercise for the SF-36 – With Test Dataset on Diskette" published by the Medical Outcomes Trust, Second Edition, August 1994. The version of the MOS SF-36 used by the TCD is identical in most respects to the published version. However, there are differences in the way that Question 3 and Question 6 on the published version of the SF-36 are worded as compared to the TCD instrument. This makes scoring of the TCD instrument challenging.

Question 3 on the published version of the SF-36 is worded "The following items are about activities that you might do during a typical day. Does your health now limit you in these activities? If so, how much?" In the TCD version of the instrument, this question was re-worded as "The following questions are about activities you might do during a typical day. First, I'd like to know if your physician has asked you not to do any of these activities. Then, I'd like you to tell me if your health limits you in these activities. That is, does your health limit you a lot, a little, or not at all?" In scoring the TCD version of the instrument, we have recoded the response "4 – Limited by doctor" as response "1 – Yes, limited a lot". This affects very few of the responses.

Question 6 on the published version of the SF-36 is worded "During the past-week, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?" with response categories "1 – Not at all, 2 – Slightly, 3 – Moderately, 4 – Quite a bit, and 5 – Extremely". On the TCD version of the instrument, this question is re-worded as "Has your health limited your social activities (like visiting with friends or close relatives)?" with response categories "1 – All of the time, 2 – Most of the time, 3 – A good bit of the time, 4 – Some of the time, 5 – A little of the time, and 6 – None of the time". In scoring the TCD version of the instrument, we translated social activity scores of 2, 3, 4, 5 and 6 to scores of 1.8, 2.6, 3.4, 4.2, and 5.0, to rescale them appropriately.

To facilitate analysis of the SF-36 as an HQL outcome measure, it is desirable to reduce the dimensionality of the instrument. We were guided in constructing summary measures by Ware JE, Kosinski, M & Keller SD. SF-36 Physical and Mental Health Summary Scales: A User's Manual. Boston, MA: The Health Institute, 1994. As described in the manual on page 4:1, "Scoring of the Physical (PCS) and Mental (MCS) Component Summary measures involve three steps. First, the eight SF-36 scales are standardized using means and standard deviations from the general U.S. population. Second, they are aggregated using weights (factor score coefficients) from the general U.S. population. Finally, aggregate PCS and MCS scores are standardized using a linear T-score transformation to have a mean of 50 and a standard deviation of 10, in the general U.S. population." Software provided in "SF-36 Physical and Mental Health Summary Scales: A User's Manual" was used to ensure that all calculations were performed correctly. *Scoring the LOT*

The Life Orientation Test (LOT) is a 13-item measure of dispositional optimism-pessimism that has been widely used to predict health outcomes, and has demonstrated good reliability and validity in patient populations. The LOT has four questions worded in a positive direction, e.g. "In uncertain times, I usually expect the best", four questions worded in a negative direction, e.g. "I hardly ever expect things to go my way", four "filler" questions designed to disguise the instrument's intent, e.g. "I enjoy my friends a lot", and an overall question, "Overall, I expect more good things to happen to me than bad". The LOT is administered during the baseline interview.

Scheier and Carver, in "Optimism, Coping, and Health: Assessment and Implications of Generalized Outcome Expectancies" (1985), note that the LOT has two major factors, one composed of items worded in a negative direction, and one composed of items worded in a positive direction, but conclude "In sum, though there is justification for examining the two halves of the scale separately, the available data base, (when taken in its entirety) suggests that it may be most reasonable to treat the scale as unidimensional for most purposes".

In our analyses, we depart somewhat from this recommendation by aggregating the LOT into three separate domains, "Optimism", "Pessimism" and "Overall Expectations". The Cronbach's alpha coefficients of reliability for the Optimism and Pessimism domains are 0.79 and 0.74. This is comparable to the value of 0.76 reported by Scheier and Carver (1985) for the 8-item scale when the pessimism items are reversed and added to the optimism items.

Scoring the COPE

The Coping Orientations to Problems Encountered (COPE) Scale assesses an individual's characteristic coping style. The COPE measures 15 different coping categories ranging from problem-focused coping to positive reinterpretation. Prior work suggests that the scale is psychometrically sound, with factor analyses of the scale yielding 15 factors, one for each subscale or coping category. The dispositional COPE is administered at the baseline interview and the situational COPE at one year post-transplant.

The 30-item scale adopted by the TCD trial selects the two highest loading items for each of the 15 factors from the original 60 item COPE scale. Note that the TCD version of the COPE and Carver's "Brief COPE" are abbreviated instruments that both evolved in parallel from the full inventory, but do not contain the same items. The COPE is scored by summing the items in each sub-scale, without reversing any items.

To facilitate use of the baseline COPE as a predictor of FACT and SF-36 HQL at one year posttransplant, it is desirable to reduce the dimensionality of the instrument. On his web site (<u>http://www.psy.miami.edu/faculty/Ccarver/sclCOPE.html</u>), Carver comments that he has no recommendations for aggregating COPE scores. However, in his paper "Coping with stress, divergent strategies of optimists and pessimists" (1986) two clusters of coping behavior are identified. In the first cluster, individuals are problem-focused and seek social support, in the second, individuals focus on and vent their emotions and disengage from the stressor.

Carver's observations form the basis for three domains created for the COPE by the TCD statisticians. These domains are "Palliative Coping", "Avoidant Coping", and "Instrumental Coping". Each of these three domains aggregates five coping categories, and is comprised of 10 questions. The table below shows the items selected from the original 60-item COPE for the TCD abbreviated version, and which items contribute to each of the three domains. The internal reliability of the Palliative, Avoidant, and Instrumental domains at baseline as measured by

Cronbach's alpha is 0.76, 0.66, and 0.65, respectively. The domains make subsequent regression analyses that use the baseline COPE as a predictor variable more tractable.

	Full 60 Item	TCD Version	TCD Domain
Positive reinterpretation & growth	1, 29, 38, 59	29, 38	Palliative Coping
Religious coping	7, 18, 48, 60	7, 18	Palliative Coping
Humor	8, 20, 36, 50	20, 36	Palliative Coping
Acceptance	13, 21, 44, 54	21, 54	Palliative Coping
Use of emotional social support	11, 23, 34, 52	23, 52	Palliative Coping
Mental disengagement	2, 16, 31, 43	31, 43	Avoidant Coping
Focus on and venting of emotions	3, 17, 28, 46	3, 28	Avoidant Coping
Denial	6, 27, 40, 57	27, 40	Avoidant Coping
Behavioral disengagement	9, 24, 37, 51	9, 24	Avoidant Coping
Substance use	12, 26, 35, 53	26, 35	Avoidant Coping
Restraint	10, 22, 41, 49	10, 41	Instrumental Coping
Use of instrumental social support	4, 14, 30, 45	4, 45	Instrumental Coping
Active coping	5, 25, 47, 58	25, 58	Instrumental Coping
Suppression of competing activities	15, 33, 42, 55	33, 55	Instrumental Coping
Planning	19, 32, 39, 56	19, 32	Instrumental Coping

 Table 3 - Selection of items and aggregate domains for the TCD COPE

Scoring the MOS Social Support

The Rand Medical Outcomes Study (MOS) Social Support Survey measures the patients perceptions of the amount and types of support and resources made available to them by their social environment or network. The scale was developed for patients in the Medical Outcomes Study, a two-year study of chronically ill patients. The scale is based on four separate social support subscales: "Emotional/Informational Support", "Tangible Support", "Affectionate Support", and "Positive Social Interaction". A higher score for an individual scale or for the overall support index indicates more support. The MOS Social Support Survey was administered at baseline and at one year post-transplant.

A description of the MOS Social Support Survey and instructions for scoring the MOS Social Support were found at <u>http://www.rand.org/health/surveys/mos.descrip.html</u>. Scores for each subscale are obtained by averaging the scores for each item in the subscale. The overall support index is the average of (1) the scores for all 18 items included in the four subscales, and (2) the score for the one additional item at the end of the survey. The scores were transformed to a 0-100 scale. Each subscale has high reliability in the TCD baseline interview data. Cronbach's alpha coefficients are 0.93, 0.82, 0.88 and 0.86 for the Emotional/Informational, Tangible, Affectionate, and Positive Social Interaction subscales, respectively. Cronbach's alpha coefficient for all 19 items is 0.95.

Scoring the CBI Self-Efficacy

The Cancer Behavior Inventory, a measure of self-efficacy, has two forms, a 33-item Long form (CBI-L version 2.0) and a 14-item Brief Form (CBI-B version 2.0). The CBI-L version 2.0 consists of 33 items describing behaviors cancer patients engage in throughout the course of their illness. The TCD instrument and the CBI-B are both abbreviated 14-item versions of the

CBI-L, but have different questions. The CBI-L version 2.0 has seven factors, shown below. The TCD abbreviated instrument selects two questions from each of factors 1, 2, 4 and 6, and three questions from each of factors 5 and 7. Factor 3 is a new scale introduced in 1999 with the adoption of version 2.0 of the CBI-L, and is not included in the TCD instrument.

- Factor 1: Maintaining activity and independence
- Factor 2: Seeking and understanding medical information
- Factor 3: Stress management
- Factor 4: Coping with treatment related side effects
- Factor 5: Accepting cancer, maintaining a positive attitude
- Factor 6: Affective regulation
- Factor 7: Seeking social support

Following each item is a scale ranging from one to nine, assessing the confidence the patient has that he or she can accomplish each item. A total efficacy score is obtained by adding the scale value of each of the items. While the CBI-L can be scored by factor, Dr. Merluzzi's website (http://www.nd.edu/~tmerluzz/,"Home of the Cancer Behavior Inventory") recommends that the CBI-B be scored by summing the 14 items. We follow this recommendation for scoring the TCD abbreviated instrument. The reliability of the TCD abbreviated CBI Self-Efficacy administered at baseline is measured by Cronbach's alpha coefficient of 0.86, which is close to the reported value of 0.85 for the CBI-B.

References for TCD HQL Analysis

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http://www.nd.edu/~tmerluzz/

http://www.psy.miami.edu/faculty/Ccarver/sclCOPE.html

http://www.rand.org/health/surveys/mos.descrip.html

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Sherbourne CD, Stewart, AL. The MOS Social Support Survey, Soc. Sci. Med. Vol 32, No. 6, 1991, pp 705-714.

Ware JE, Kosinski, M & Keller SD. SF-36 Physical and Mental Healthy Summary Scales: A User's Manual. Boston, MA: The Health Institute, 1994.

FUNCTIONAL ASSESSMENT OF CANCER THERAPY (FACT) (VERSION 3)

I'm going to read a list of statements that describe situations other people with your illness have said are important. Please indicate how true each statement has been for you during the past seven days using the white sheet of paper and the top answer key -- "not at all" to "very much."

PHYSICAL WELL-BEING

Dur	ing the past 7 days:	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.	In general, I feel sick	0	1	2	3	4
7.	I am forced to spend time in bed	0	1	2	3	4
Ŋ	THINKING ABOUT THOSE LAST 7 QUESTIONS, HOW MUCH YOU SAY YOUR <u>PHYSICAL WELL-BEING</u> AFFECTS YOUR OF LIFE (using the second answer key that goes from 0 to 10)?		0 1 Not at		Circle one 5 6 7 8	

SOCIAL/FAMILY WELL-BEING

		what	a bit	much
)	1	2	3	4
)	1	2	3	4
)	1	2	3	4
)	1	2	3	4
)	1	2	3	4
)	1	2	3	4
)	1	2	3	4
))))) 1) 1) 1) 1) 1	1 2 1 2 1 2 1 2 1 2 1 2 1 2 1 2 1 2 1 2 1 2	1 2 3 1 2 3 1 2 3 1 2 3 1 2 3 1 2 3 1 2 3 1 2 3 1 2 3

YOU SAY YOUR SOCIAL/FAMILY WELL-BEING AFFECTS YOUR QUALITY OF LIFE (using the second answer key that goes from 0 to 10)? 6 7 10

3 4 5 8 9 Not at all Very much

0 1 2

RELATIONSHIP WITH DOCTOR

The next three questions are about your relationship with your doctor. The doctor I would like you to consider is the doctor you presently have the most contact with.

During the past 7 days:	Not at all	A little bit	Some- what	Quite a bit	Very much
17. I have confidence in my doctor(s)	0	1	2	3	4
18. My doctor is available to answer my questions	0	1	2	3	4

19.THINKING ABOUT THOSE LAST 2 QUESTIONS, HOW MUCH WOULD YOUCircle one numberSAY YOUR RELATIONSHIP WITH THE DOCTOR AFFECTS YOUR012345678910QUALITY OF LIFE (using the second answer key that goes from 0 to 10)?Not at allNot at allVery much

EMOTIONAL WELL-BEING

<u>Duri</u>	ng the past 7 days:	Not at all	A little bit	Some- what	Quite a bit	Very much
20.	I feel sad	0	1	2	3	4
21.	I am proud of how I'm coping with my illness	0	1	2	3	4
22.	I am losing hope in the fight against my illness	0	1	2	3	4
23.	I feel nervous	0	1	2	3	4
24.	I worry about dying	0	1	2	3	4
25.	I worry that my condition will get worse	0	1	2	3	4

26.	THINKING ABOUT THOSE LAST 6 QUESTIONS, HOW MUCH WOULD						C	lirc	le o	ne r	num	ber
	-					4	5	6	7	8	9	10
	OF LIFE (using the second answer key that goes from 0 to 10)?								1	Very	y m	uch

FUNCTIONAL WELL-BEING

During the past 7 days:	Not at all	A little bit	Some- what	Quite a bit	Very much
27. I am able to work (include work in home)	0	1	2	3	4
28. My work (including work in home) is fulfilling	0	1	2	3	4
29. I am able to enjoy life "in the moment"	0	1	2	3	4
30. I have accepted my illness	0	1	2	3	4
31. I am sleeping well	0	1	2	3	4
32. I am enjoying my usual leisure pursuits	0	1	2	3	4
33. I am content with the quality of my life right now	0	1	2	3	4
34. THINKING ABOUT THOSE LAST 7 QUESTIONS, HOW MUC	H WOULD			Circle one	number
YOU SAY YOUR FUNCTIONAL WELL-BEING AFFECTS YO	UR QUALIT	Y 0 1	2 3 4	5 6 7 8	3 9 10

OF LIFE (using the second answer key that goes from 0 to 10)?

Very much

Not at all

ADDITIONAL CONCERNS

During the past 7 days:	Not at all	A little bit	Some- what	Quite a bit	Very much
35. I am concerned about keeping my job (include work at	•				
home)	0	1	2	3	4
36. I feel distant from other people	0	1	2	3	4
37. I worry that the transplant will not work	0	1	2	3	4
38. My side effects are worse than I had imagined	0	1	2	3	4
39. I have a good appetite	0	1	2	3	4
40. I like the appearance of my body	0	1	2	3	4
41. I am able to get around a room by myself	0	1	2	3	4
42. I get tired easily	0	1	2	3	4
43. I am interested in having sex	0	1	2	3	4
44. I have concerns about my ability to have children	0	1	2	3	4
45. I have confidence in the transplant nurses	0	1	2	3	4
46. I regret making the decision to have a bone marrow transplant	0	1	2	3	4
 47. THINKING ABOUT THOSE LAST 12 QUESTIONS, HOW MUC YOU SAY THESE <u>ADDITIONAL CONCERNS</u> AFFECT YOUR OF LIFE (using the second answer key that goes from 0 to 10)? 	0 1 Not at a		Circle one 5 6 7 8 Ve		

VO2, 04/95

BMT MODULE

For each symptom I'm going to read, I'd like you to tell me whether or not you have experienced this symptom during the past 14 days. Then, if you have experienced that symptom during the past 14 days, indicate how severe that symptom was and how much that symptom interfered with your life during the past 14 days. You'll need the yellow sheet of paper.

Page 5

During the past 14 days, have you experienced (if no, code "not at all"):

			A. <u>Severi</u>	ty		B. Interference					
		Not at all	A little bit	Quite a bit	Very much	Not at all	A little bit	Quite a bit	Very much		
1.	Loss of appetite	1	2	3	4	1	2	3	4		
2.	Nausea	1	2	3	4	1	2	3	4		
3.	Vomiting	1	2	3	4	1	2	3	4		
4.	Chills	1	2	3	4	1	2	3	4		
5.	Diarrhea	1	2	3	4	1	2	3	4		
6.	Constipation	1	2	3	4	1	2	3	4		
7.	Painful urination	1	2	3	4	1	2	3	4		
8.	Skin problems										
	a. Rashes	1	2	3	4	1	2	3	4		
	b. Dryness	1	2	3	4	1	2	3	4		
	c. Sweating	1	2	3	4	1	2 ·	3	4		
	d. Painful skin	1	· 2	3	4	1	2	3	4		
	e. Skin ulcers	1	2	3	4	1	2	3	4		
	f. Overall	1	2	3	4	1	2	3	4		
9.	Hair loss	1	2	3	4	1	2	3	4		
10.	Nail loss	1	2	3	4	1	2	3	4		
11.	Eye problems										
	a. Dryness	1	2	3	4	1	2	3	4		
	b. Grittiness	1	2	3	4	1	2	3	4		
	c. Burning	1	2	3	4	1	2	3	4		
	d. Blurring	1	2	3	4	1	2	3	4		
	e. Sensitivity to light	1	2	3	4	1	2	3	4		
	f. Cataracts	1	2	3	4	1	2	3	4		
	g. Overall	1	2	3	4	1	2	3	4		
12.	Mouth/throat problems										
	a. Dryness	1	2	3	4	1	2	3	4		
	b. Soreness	1 -	2	3	4	1	2	3	4		
	c. Burning	1	2	3	4	1	2	3	4		
	d. Overall	1	2	3	4	1	2	3	4		
13.	Teeth problems (dental caries, etc.)	` 1	2	3	4	1	2	3	4		
14.	Abnormal sense of taste for food or										
	drink	1	2	3	4	1	2	3	4		
15.	Heartburn	1	2	3	4	1	2	3	4		
16.	Abdominal pain	1	2	3	4	1	2	3	4		

TCD

6 Recip

Recipient NMDP ID:

		A. <u>Severity</u>					B. Interference					
		Not at all	A little bit	Quite a bit	Very much	Not at all	A little bit	Quite a bit	Very much			
17.	Weight loss	1	2	3	4	1	2	3	4			
18.	Sinusitis	1	2	3	4	1	2	3	4			
19.	Runny nose	1	2	3	4	1	2	3	4			
20.	Breathing problems											
	a. Coughing	1	2	3	4	1	2	3	4			
	b. Wheezing	1	2	3	4	1	2	3	4			
	c. Bronchitis	1	2	3	4	1	2	3	4			
	d. Asthma	1	2	3	4	1	2	3	4			
	e. Overall	1	2	3	4	1	2	3	4			
21.	Painful joints											
	a. Hip joints	1	2	3	4	1	2	3	4			
	b. Other joints	1	2	3	4	1	2	3	4			
	c. Overall	1	2	3	4	1	2	3	4			
22.	Painful muscles	1	2	3	4	1	2	3	4			
23.	Infections											
	a. Varicella zoster (VZV)	1	2	3	4	1	2	3	4			
	b. Herpes Simplex	1	2	3	4	1	2	3	4			
	c. Cytomegalovirus (CMV)	1	2	3	4	1	2	3	4			
	d. Pneumonia	1	2	3	4	1	2	3	4			
	e. Measles	1	2	3	4	1	2	3	4			
	f. Chickenpox	1	2	3	4	1	2	3	4			
	g. Shingles	1	2	3	4	1	2	3	4			
	h. Overall	1	2	3	4	1	2	3	4			
24.	Chronic graft-versus-host disease											
	(GVHD)	1	2	3	4	1	2	3	4			
25.	Minor symptoms or ailments (common											
	cold, flu, migraine, etc.)	1	2	3	4	1	2	3	4			
26.	Worried by fear of infection	1	2	3	4	1	2	3	4			
27.	Worried by thoughts about relapse or	_	_			_		-				
	dying	1	2	3	4	1	2	3	4			
28.	Difficulty in maintaining your attention	1	2	n	4	1	2	2	4			
20	and train of thought	1	2	3	4	1	2	3	4			
29.	Difficulty in reasoning and thinking clearly	1	2	3	4	1	2	3	4			
30.	Difficulty in concentrating on things, like	1	<i>L.</i>		7	1	L	5				
50.	reading a newspaper or watching											
	television	1	2	3	4	1	2	3	4			

31. Have you experienced any other symptoms that I didn't ask you about?

A. <u>Severity</u>					B. Interference								
	Not at all	A little bit		Very much	Not at all	A little bit	-	Very much					
	1	2	3	4	1	2	3	4					
	1	2	3	4	1	2	3	4					

: L_____
PERCEIVED HEALTH QUESTIONNAIRE (PHQ) and LADDER OF LIFE

The purple sheet has a picture of a health ladder with 10 steps. Suppose that the top of the ladder represents perfect health for you and the bottom of the ladder represents the worst that your health could be.

1. On which step would you say your health is right now?

2. On which step would you say the health of the average person your age is?

3. On which step would you say your health was before your illness?

4. On which step would you say your health will be one year from now?

The purple sheet also has a ladder representing the "Ladder of Life." The top of the ladder represents the best possible life for you. The bottom of the ladder represents the worst possible life for you.

On which step of the ladder do you feel you personally stand at the present time? 1.

2. On which step would you say you stood before your illness?

you

3. Thinking about your future, on which step do you think you will stand about one year from now?



Best possible . life

Worst possible life

SOCIAL SUPPORT RAND MEDICAL OUTCOMES STUDY (MOS)

People sometimes look to other people for companionship, assistance, or other types of support. I'm going to ask you how often certain kinds of support are available to you. When you answer these questions, think about your current relationships with other people. You will need the **pink** sheet to answer these questions. As you see, your answers can be anywhere from "none of the time" which is a 1 to "all of the time" which is a 5.

In general, how often is there . . .

		None of the time	A little of the time	Some of the time	Most of the time	All of the time
1.	Someone to help you if you were confined to bed	1	2	3	4	5
2.	Someone you can count on to listen to you when you need to		-	-		-
	talk	1	2	3	4	5
3.	Someone to give you good advice about a crisis	1	2	3	4	5
4.	Someone to take you to the doctor if you need it	1	2	3	4	5
5.	Someone who shows you love and affection	1	2	3	4	5
6.	Someone to have a good time with	1	2	3	4	5
7.	Someone to give you information to help you understand a					
	situation	1	2	3	4	5
8.	Someone to confide in or talk about yourself or your					
	problems	1	2	3	. 4	5
9.	Someone who hugs you	1	2	3	4	5
10.	Someone to get together with for relaxation	1	2	3	4	5
11.	Someone to prepare your meals if you were unable to do it					
	yourself	1	2	3	4	5
12.	Someone whose advice you really want	1	2	3	4	5
13.	Someone to do things with to help you get your mind off					
	things	1	2	3	4	5
14.	Someone to help with daily chores if you were sick	1	2	3	4	5
15.	Someone to share your most private worries and fears with	1	2	3	4	5
16.	Someone to turn to for suggestions about how to deal with a					
	personal problem	1	2	3	4	5
17.	Someone to do something enjoyable with	1	2	3	4	5
18.	Someone who understands your problems	1	2	3	4	5
19.	Someone to love and make you feel wanted	1	2	3	4	5

I have been asking about support you have been **receiving** from others. The last question asks about support you **give** others. In general, how often is there . . .

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	
20. Someone to take care of	1	2	3	4	5	

BERKMAN & SYME SOCIAL NETWORK INDEX (SNI)

Now, I'm going to ask you some questions about your relationships with your family, friends, co-workers, and so on. We are interested in how supported you feel by these people.

1. First, about how many close friends do you have? These would be people you feel at ease with and can talk to about what is on your mind.

SNI __ (#)

2. How many family members or close relatives do you have?

> SNI _____ (#)

3. How many of these friends or relatives do you see at least once a month?

> SNI _ (#)

4. Do you belong to any of the following groups?

	Yes	No
A social or recreational group	1	2
A labor union, commercial group, or professional organization	1	2
A church group	1	2
A group concerned with children (PTA, Boy Scouts)	1	2
A group concerned with community betterment, charity, or service	1	. 2
A support group	1	2

Any other group (Describe:_ ì

Is there anything you would like to add at this point about your relationships with people and how those were affected by your illness?

CANCER BEHAVIOR INVENTORY: SELF-EFFICACY (CBI)

Now I will ask you some questions about things that a person might do when receiving treatment for cancer. We are interested in your judgment of how confident you are that you can do those things. You will need the blue sheet for these questions. Do you have that?

I'll read each question. Then, you should tell me how confident you are that you can do that particular behavior. Your answer can be anywhere from "1," which means that you aren't at all confident, to "9," which means that you are completely confident.

How confident are you about . . .

		Not at all confident	t			derately nfident	,		Tota confide	•
1.	Coping with physical changes	1	2	3	4	5	6	7	8	9
2.	Maintaining a positive attitude	1	2	3	4	5	6	7	8	9
3.	Expressing negative feelings about cancer	1	2	3	4	5	6	7	8	9
4.	Keeping busy with activities	1	2	3	4	5	6	7	8	9
5.	Maintaining your independence	1	2	3	4	5	6	7	8	9
6.	Seeking consolation	1	2	3	4	5	6	7	8	9
7.	Maintaining a sense of humor	1	2	3	4	5	6	7	8	9
8.	Actively participating in treatment decisions	1	2	3	4	5	6	7	8	9
9.	Sharing feelings of concern	1	2	3	4	5	6	7	8	9
10.	Maintaining hope	1	2	3	4	5	.6	7	8	9
11.	Managing nausea and vomiting	1	2	3	4	5	6	7	8	9
12.	Seeking support from people and groups outside your family	. 1	2	3	4	5	6	7	8	9
13.	Expressing personal feelings of anger and hostility	1	2	3	4	5	6	7	8	9
14.	Seeking information about cancer or cancer treatments	1	2	3	4	5	6	7	8	9

LIFE ORIENTATION TEST (LOT)

Let's go now to some questions about how you generally feel. To answer these questions, you'll need the **green** sheet. Do you have it? As you can see, you would tell me "0" if you strongly disagree with the item, "1" if you disagree, "2" if you are neutral, "3" if you agree, and "4" if you strongly agree.

As I ask these questions, try to be as honest as you can because there aren't any right or wrong answers. Also try not to let your answer to one question influence how you answer another.

		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1.	In uncertain times, I usually expect the best	0	1	2	3	4
2.	It's easy for me to relax	0	1	2	3	4
3.	If something can go wrong for me, it will	0	1	2	3	4
4.	I always look on the bright side of things	0	1	2	3	4
5.	I'm always optimistic about my future	0	1	2	3	4
6.	I enjoy my friends a lot	0	1	2	3	4
7.	It's important for me to keep busy	0	1	2	3	4
8.	I hardly ever expect things to go my way	0	1	2	3	4
9.	Things never work out the way I want them to	0	1	2	3	4
10.	I don't get upset too easily	0	1	2	3 .	4
11.	I'm a believer in the idea that "every cloud has a silver lining"	0	1	2	3	4
12.	I rarely count on good things happening to me	0	1	2	3	4
13.	Overall, I expect more good things to happen to me than bad	0	1	2	3	4

Α

COPING ORIENTATIONS TO PROBLEMS ENCOUNTERED (COPE)--DISPOSITIONAL

We are interested in how people respond when they confront difficult or stressful problems. There are lots of ways to try to deal with problems. The next set of questions asks you what you <u>usually</u> do when you encounter difficulties or problems in your life.

Using the **tan** sheet of paper, tell how much each item I'll read describes your reactions. There are no "right" or "wrong" answers, so choose the most accurate answer for <u>you</u>--not what you think "most people" would say or do. Indicate what <u>you</u> usually do when <u>you</u> experience a problem.

					A	
L			Don't at all	A little bit	medium amount	A lot
	1.	I get upset and let my emotions out	1	2	3	4
	2.	I try to get advice from someone about what to do	1	2	3	4
	3.	I put my trust in God	1	2	3	4
	4.	I admit to myself that I can't deal with it, and quit trying .	1	2	3	4
	5.	I restrain myself from doing anything too quickly	1	2	3	4
	6.	I seek God's help	1	2	3	4
	7.	I make a plan of action	1	2	3	4
	8.	I make jokes about it	1	2	3	4
	9.	I accept that this has happened and that it can't be changed	1	2	3	4
	10.	I try to get emotional support from friends or relatives		2		
	11.	I just give up trying to reach my goal	1	.2 *	3 .	4
	12.	I take additional action to try to get rid of the problem	1	2	3	4
	13.	I try to lose myself for a while by drinking alcohol or taking				
		drugs	1 .	2	3	4
	14.	I refuse to believe that it has happened	1	2	3	4
	15.	I let my feelings out	1	2	3	4
	16.	I try to see it in a different light, to make it seem more				
		positive	1	2	3	4
	17.	I sleep more than usual	1	2	3	4
	18.	I try to come up with a strategy about what to do	1	2	3	4
	19.	I focus on dealing with this problem and, if necessary, let				
		other things slide a little	1	2	3	4
	20.	I drink alcohol or take drugs, in order to think about it less	1	2	3	4
	21.	I kid around about it	1	2	3	4
	22.	I look for something good in what is happening	1	2	3	4
	23.	I pretend that it hasn't really happened	1	2	3	4
	24.	I make sure not to make matters worse by acting too soon	1	2	3	4
	25.	I go to movies or watch TV to think about it less	1	2	3	. 4
	26.	I ask people who have had similar experiences what they	_	_		
		did	1	2	3	4
	27.	I talk to someone about how I feel	1	2	3	4
	28.	I learn to live with it	1	2	3	4
	29.	I put aside other activities in order to concentrate on this .	1	2	3	4
	30.	I do what has to be done, one step at a time	1	2	3	4

Are there other ways you respond to difficult or stressful situations that you have found helpful?

COPING ORIENTATIONS TO PROBLEMS ENCOUNTERED (COPE) (SITUATIONAL)

Now, I would like you to think specifically of a difficult or stressful situation you have had to deal with in the past 14 days. Tell me briefly about that.

Using the **tan** sheet of paper, tell me how much each item I'll read best describes how you reacted to that situation. Again, there are no "right" or "wrong" answers, so choose the most accurate answer for <u>you</u>-not what you think "most people" would have said or done. Indicate what <u>you</u> did when <u>you</u> experienced this particular problem.

		Don't at all	A little bit	A medium amount	A
		at all	on	amount	101
1.	I got upset and let my emotions out	1	2	3	4
2.	I tried to get advice from someone about what to do	1	2	3	4
3.	I put my trust in God	1	2	3	4
4.	I admitted to myself that I couldn't deal with it, and quit				
	trying	1	2	3	4
5.	I restrained myself from doing anything too quickly	1	2	3	4
6.	I sought God's help	1	2	3	4
7.	I made a plan of action	1	2	3	4
8.	I made jokes about it	. 1	2	3	4
9.	I accepted that this has happened and couldn't be changed	1	2	3	4
10.	I tried to get emotional support from friends or relatives	1	2	3	4
11.	I just gave up trying to reach my goal	1	2	3	4
12.	I took additional action to try to get rid of the problem	1	2	3	4
13.				-	
	taking drugs	1	2	3	4
14.	I refused to believe that it had happened	1	2	3	4
15.	l let my feelings out	1	2	3	4
16.	I tried to see it in a different light, to make it seem more			2	
	positive	1	2	3	4
17.	-	1	2	3	4
18.	•	1	2	3	4
19.		-		5	·
	let other things slide a little	1	2	3	4
20.	I drank alcohol or took drugs, in order to think about it less	1	2	3	4
21.	I kidded around about it	1	2	3	4
22.	I looked for something good in what was happening	1	2	3	4
23.	I pretended that it hadn't really happened	1	2	3	à
24.	I made sure not to make matters worse by acting too soon	1	2	3	4
25.	I went to movies or watched TV to think about it less	1	2	3	4
26.	I asked people who had had similar experiences what they	-	2	5	4
	did	1	2	3	4
27.	I talked to someone about how I felt	1	2	3	4
28.	I learned to live with it	1	2	3	4
29.	I put aside other activities in order to concentrate on it	1	2	3	
	I did what had to be done, one step at a time	1	2	3	4
			<i>L</i>	5	-+

Are there other ways you responded to that situation that you found helpful?

The next set of questions has to do with your working at a job or in the home.

- 1. Which of the following best describes your current job status?
 - 1 = Employed outside the home, full-time 6 = Temporarily disabled
 - 2 = Employed outside the home, part-time 7 = Permanently disabled
 - the nome, part-time 7 = 1 cm
 - 3 = Homemaker

8 =Student

4 = Retired

- 9 =Other (e.g., volunteer)
- 5 = Unemployed, looking for work
- 2. What kind of work do you do at the present time? (Include work done in the home.)

3. At the present time, how many hours do you work each week for which you are paid? How many for which you are not paid?

_____ paid hours ______ unpaid hours

4. Have you attempted to work/go to school but found that you weren't able to?

(1) Yes (2) No

(If yes) What prevents you from working/going to school at the present time?

5. Is your work/school work as important to you now as it was before your diagnosis? (Explore.)

- (1) More important
- (2) About the same importance

(3) Less important

6. Have you changed your goals concerning your work/education as a result of your diagnosis? (Explore.)

(1) My goals haven't changed

(2) My goals have changed slightly

- (3) My goals have changed quite a bit
- (4) My goals have changed completely

CENTERS FOR EPIDEMIOLOGICAL STUDIES OF DEPRESSION (CES-D)

Now, I am going to ask you some questions about things that may have happened to you during the past week. It's important to remember that you think about the <u>past week only</u> when you answer these questions. To answer these questions, you'll need the **red** sheet of paper. As you can see, for each question, you can answer that this was true for you less than one day, for 1 to 2 days, for 3 to 4 days, or for 5 to 7 days.

During the past week . . .

		Less than 1 day	1 to 2 days	3 to 4 days	5 to 7 days
1.	I was bothered by things that usually don't bother me	0	1	2	3
2.	I did not feel like eating; my appetite was poor	0	1	2	3
3.	I felt that I could not shake off the blues even with help from				
	my family or friends	0	1.	2	.3
4.	I felt that I was just as good as other people	0	1	2	3
5.	I had trouble keeping my mind on what I was doing	0	1	2	3
6.	I felt depressed (blue or down)	0	1	2	3
7.	I felt that everything I did was an effort	0	1	2	3
8.	I felt hopeful about the future	0	1	2	3
9.	I thought my life had been a failure	0	1	2	3
10.	I felt fearful	0	1	2 ·	3
11.	My sleep was restless	0	1	2	3
12.	I was happy	0	1	2	3
13.	I talked less than usual	0	1	2	3
14.	I felt lonely	0	1	2	3
15.	People were unfriendly	0	1	2	3
16.	I enjoyed life	0	1	2	3
17.	I had crying spells	0	1	2	3
18.	I felt sad	0	1	2	3
19.	I felt that people disliked me	0	1	2	3
20.	I could not "get going"	0	1	2	3

BRADBURN AFFECT BALANCE SCALE

For the next questions that ask about your experiences of the past few weeks, please answer "no," "sometimes," or "often." During the past few weeks, have you ever felt . . .

		No	Sometimes	Often
1.	Particularly excited or interested in something	1	2	3
2.	So restless that you couldn't sit still long in a chair	1	2	3
3.	Proud because someone complimented you on something you had done	1	2	3
4.	Very lonely or remote from other people	1	2	3
5.	Pleased about having accomplished something	1	2	3
6.	Bored	1	2	3
7.	On top of the world	1	2	3
8.	Depressed or very unhappy	1.	2	3
9.	That things were going your way	1	2	3
10.	Upset because someone criticized you	1	2	3

SEXUAL FUNCTIONING ITEMS

Sometimes the diagnosis and treatment of cancer can affect a person's sexual activity or feelings of sexual attractiveness to others. While I know the following questions are personal, it's important to know how cancer and cancer treatments can affect this part of your life. We appreciate your answering these questions as best as you can. You'll need the **orange** sheet of paper.

1. Has your doctor told you not to engage in sexual intercourse?

(1) Yes (go to question 5, next page)

(2) No (go to remaining questions)

2. Have you been sexually active in the past six months?

(1) Yes

(2) No (go to question 4, next page)

3. Have you been sexually active in the past four weeks?

(1) Yes (go to remaining questions)

(2) No (go to question 4, next page)

How much has each of the following been a problem to you over the past 4 weeks?

For males:	Not a problem	A little problem	A definite problem	A serious problem
Lack of sexual interest	1	2	3	4
Difficulty in achieving/keeping an erection	1	2	3	4
Premature ejaculation	1	2	3	4
Difficulty in having an orgasm	1	2	3	4
The appearance of my body	1	2	3	4
Seeing myself as sexually attractive	1	2	3	4
For females:	Not a problem	A little problem	A definite problem	A serious problem
Lack of sexual interest	1	2	3	4
Vaginal dryness	1	2	3	4
Painful intercourse	1	2	3	4
Difficulty having an orgasm	1	2	3	4
The appearance of my body	1	2	3	4
Seeing myself as sexually attractive	1	2	3	Λ

A Strategies

Have any of the following been a reason for your not being sexually active in the past month? (Skip this question if 4. answered yes to question 3.)

	Yes	No	N/A
No partner	1	2	3
No opportunity	1	2	3
Lack of sexual interest	1	2	3
The appearance of my body	1	2	3
Seeing myself as sexually attractive	1	2	3
M - Problems in achieving/keeping an erection	1	2	3
M - Problems in having an orgasm	1	2	3
M - Premature ejaculation	1	2	3
F - Vaginal dryness	1	2	3
F - Painful intercourse	1	2	3
F - Difficulty having an orgasm	1	2	3

Even though your doctor asked you not to engage in sexual intercourse, have any of the following been a problem for you 5. over the past four weeks? (Skip this question if answered no to question 1.)

	Yes	No	N/A
Lack of sexual interest	1	2	3
The appearance of my body	1	2	3
Seeing myself as sexually attractive	1	2	3

6. For females: Have you experienced any of the following symptoms?

	Yes	No
Hot flashes	1	2
Difficulty with bladder control when laughing or crying	1	2
Difficulty with bladder control at other times	1	2
Waking up at night	1	2
Difficulty falling asleep	1	2
Heavy menstrual flow	1	2
Vaginal discharge	1	2
Vaginal bleeding or spotting	1	2
Genital itching/irritation	1	2
Vaginal dryness	1	2
Pain with intercourse	1	2
Joint pains	1	2
Night sweats	1	2
Cold sweats	1	2
Difficulty concentrating	1	2
Irritability	1	2
Difficulty dealing with the idea of menopause	1	2
Wondering if my menopause is different than a "regular" menopause	1	2
hat was the date of your last menstrual period?//	Don	't knov

- 7. For females: Have you ever taken hormone replacement therapy (in other words, have you taken estrogen in any form other than birth control pills?
 - (1) Yes (go to question 8)
 - (2) No (go to question 9)
 - 8. If yes, which of the following best describes your situation?
 - (1) I took hormone replacement therapy up until my diagnosis and then stopped, and I have not started again.
 - (2) I took hormone replacement therapy much before my diagnosis and was not taking it at that time, and I have not started again.
 - (3) I began taking hormone replacement therapy after my diagnosis and am currently taking it.
 - (4) I began taking hormone replacement therapy after my diagnosis, but I am not currently taking it.
- 9. Excluding fertility issues, has your health care provider discussed the effect of your transplant on sexual activity or functioning?
 - (1) Yes (2) No
- 10. (For all respondents:) Is there any other problem you've had in this area that I didn't ask you about?

MEDICAL OUTCOMES STUDY SHORT FORM 36 (MOS SF36)

In this section, I'm going to ask for your views about your health. This information will help us keep track of how you feel and how well you are able to do your usual activities.

- 1. In general, would you say your health is:
 - (1) Excellent
 - (2) Very good
 - (3) Good
 - (4) Fair
 - (5) Poor
- 2. Compared to 1 year ago, how would you rate your health in general now?
 - (1) Much better than 1 year ago
 - (2) Somewhat better now than 1 year ago
 - (3) About the same
 - (4) Somewhat worse now than 1 year ago
 - (5) Much worse than 1 year ago
- 3. The following questions are about activities you might do during a typical day. First, I'd like to know if your physician has asked you not to do any of these activities. Then, I'd like you to tell me if your <u>health</u> limits you in these activities. That is, does your health limit you a lot, a little, or not at all?

	Yes, limited a lot	Yes, limited a little	No, not limited at all	Limited by doctor
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3	A
strenuous sports	1	2	3	4
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3	4
Lifting or carrying groceries	1	2	3	4
Climbing several flights of stairs	1	2	3	4
Climbing one flight of stairs	1	2	. 3	-+
	1	2	3	. 4
Bending, kneeling, or stooping	1	2	3	4
Walking more than 1 mile	1	2	3	4
Walking several blocks	1	2	3	4
Walking 1 block	1	2	3	4
Bathing or dressing yourself	1	2	3	4

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

	Yes	No
Cut down the amount of time you spent on work or other activities	1	2
Accomplished less than you would like	1	2
Were limited in the kind of work or other activities	1	2
Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

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	Yes	No
Cut down the amount of time you spent on work or other activities	1	2
Accomplished less than you would like	1	2
Didn't do work or other activities as carefully as usual	1	2

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

(0) Not at all	(1) Slightly	(2) Moderately	(3) Quite a bit	(4) Extremely

7. How much bodily pain have you had during the past 4 weeks?

(1) Slightly

(0) None (1) Very mild (2) Mild (3) Moderate (4) Severe (5) Very severe

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and 8. housework)?

(0) Not at all

(2) Moderately (3) Quite a bit (4) Extremely

9. 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 answer that comes closest to the way you have been feeling. Use the first answer key on the gray sheet of paper.

• •	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of pep	1	2	3	4	5	6
Have you been a very nervous person	1	2	3	4	5	6
Have you felt so down in the dumps nothing could cheer you up	- 1	2	3	4	5	6
Have you felt calm and peaceful	1	2	3	4	5	6
Did you have a lot of energy	1	2 .	3	4	5	6
Have you felt downhearted and blue	1	2	3	4	5	6
Did you feel worn out	1	2	3	4	5	6
Have you been a happy person	1	. 2	3	4	5	6
Did you feel tired	1	2	3	4	5	6
Has your health limited your social activities (like visiting with friends or close relatives)	1	2	2		<i>_</i>	,
close relatives)	1	2	3	4	5	6

10. Please choose the answer that best describes how true or false each of the following statements is for you. Use the second answer key on the gray sheet.

	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
I seem to get sick a little easier than other people	1	2	3	4	5
I am as healthy as anybody I know	1	2	3	4	5
I expect my health to get worse	1	2	3	4	5
My health is excellent	1	2	3	4	5

DEMOGRAPHIC INFORMATION

This last set of questions will provide us with information about you, your background, and your family. Remember, all your answers will be kept strictly confidential.

1. What is your current marital status?

1 = single	4 = separated
2 = married	5 = divorced
3 = cohabiting	6 = widowed

2. Do you have any living children? (If yes)

How many?

What are their ages?

3. What is the total annual income in your household from all sources (before taxes)?

1 = 1 less than \$10,000	5 = \$50,000 - \$69,999
2 = \$10,000 - \$19,999	6 = \$70,000 - \$99,999
3 = \$20,000 - \$29,999	7 = \$100,000 or more
4 = \$30,000 - \$49,999	

4. How many years of education have you completed?

1 = do not have high school degree	5 = have attended/currently attending a 4-year college
2 = high school graduate or GED	6 = 4-year college degree
3 = have attended/currently attending a 2-year	7 = have completed/currently pursuing some graduate work
college or trade school	8 = Master's degree
4 = 2-year college degree or trade degree	9 = Doctorate

5. What is your primary source of your health insurance?

1 = Present employment	5 = Veterans Administration
2 = Previous employment	6 = Self-pay
3 = Medicare	7 = None
4 = Medicaid	8 = Other

6. Approximately what part of your medical expenses over the past year were covered by health insurance?

1 = All (or almost all)	4 = Between one-fourth and one-half
2 = More than three-fourths but less than all	5 = Less than one-fourth
3 = Between one half and three-fourths	

7. Are you currently receiving any financial support for disability? 1 = Yes = 2 = No

That's all the questions we're going to ask you today. We appreciate your assistance with this study to help us better understand the feelings and concerns of individuals who are about to undergo transplant.

At this time, I'd like to remind you that I will be calling you again in approximately three months to see how you are doing and to ask you a much shorter set of questions. Do you have any questions for me right now? Is there anything you want to add that you think would be important for us to know?

I have one more request before we hang up. It's important that I get the names of two people who do not live with you, who can tell me how to locate you if I can't catch you by telephone. Are there two people who you would feel comfortable with me calling in case I have trouble locating you for the next interview? Would you give me their names?

Name:		····· • • • • • • • • • • • • • • • • •	 	
Address:			 	
Phone:				
Name:			 	
Address:				
Phone:	· · · · · · · · · · · · · · · · · · ·		 · · · ·	

Thank you again for your help.

Recipie NMDP	ID:	-	Recipient Last Name:			
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studies perform	Number of Unknown Origin (Third Party) Cells				y cells by (+)	(Insert numbe - Bone marrow (BM) - Peripheral blood mononuc - T-cells - B-cells
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Provide date(Cell Method Type (See (See valid list valid list below) below)				titative metho	Valid Method Codes in box above to indicat 4 - Po Jization (FISH) 5 - HL 3th 6 - VN 3th 7 - Oil
Chirr m Studies (Date Month Day Year				* If performed by non-quantitative method, indicate the presenc	Valid Method (Insert number in box above t 1 - Standard cytogenetics 2 - Fluorescent in situ hybridization (FISH) 3 - Restriction fragment-length polymorphisms (RFLP)

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National Marrow Denor Program® Recipient Baseline and	Unrelated 10	Recipient NMDP ID:
Transplant Data	Recipient	
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	Recipient Local ID (optional):	
Registry Use Only		
ouquente	ROD 7 Today's Date: Month Da	and here have been been a second seco
Number:	Date of Transplant for which the	
1 F ···	TXDT is being completed:	Month Day Year
Received:	Product type: Marrow (Form 120)	PBSC Cord blood (Form 520) (Form 620)
Research blood samples should be co	llected before initiation of prepara	ative regimen and sent to Blood Centers
of the Pacific, Irwin Center. See Transp	plant Center Manual of Operations	for instructions.
1. Recipient name:	(please print)	Reg Use On
2. a. State of residence of recipient (for residence of recipient and the state of residence of recipient and the state of	dents of USA): <u>STATE</u>	
b. Zip or postal code for place of recipien		ZIA
c. Country if non-resident of USA:		
•		
3. Does the recipient have a U.S. Social Sec		irance Number)? SSNYN
1 🛛 yes — 4. Social Security	Number/Social Insurance Number:	
- no	SSN REAS	
	or Canadian) citizen	
2 🗆 Less than 3 🗖 Other, spe		
6. Sex: 1 Male 2 Female X.SEX		RACEI
7. Race: If the recipient's parents are from t	wo separate of the following groups, ch	
Caucasian/White	Asian/Pacific Islander	18 🛛 Mexican American or Chicano
 North American or European Middle East or North Coast of 	9 🔲 South Asian 10 🔲 Filipino (Pilipino)	19 South or Central American 20 Hispanic, Otherwise not specified
Africa	11 D Hawaiian or Pacific Islander	Native American
3 D White, Otherwise not specified	12 🔲 Japanese	21 Alaskan Native or Aleut
Black	13 🔲 Korean 14 🔲 Chinese	Tribe:
4 🗍 African American	15 🔲 Southeast Asian	Tribe:
5 African (both parents born in Africa)	16 Asian/Pacific Islander, Otherwise not specified	23 🔲 Native American,
6 □ Caribbean 7 □ South or Central American	Hispanic	Otherwise not specified Other
8 Black, Otherwise not specified	17 D Puerto Rican or Caribbean	24 Other, specify:
8. Date of birth:	XBIRTHDT	
Month Day	Year	and the second
3 ¹		Mail this form to: The NMDP Registry
		Suite 500

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3433 Broadway Street-NE. Minneapolis, MN 55413 "Retain a copy at the transplant center.







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	- Recipient Last Name:		
(I Status of Recipient	Prior to Conditioning		
10. Did the recipient receive blood t	ransfusions at any time prior to	conditioning? BTPRIOR	
1 🗆 yes> 2 🗔 no 3 🗔 not known	2 🗆 6 – 10 6 🗆	hate) of donor exposures: 31 - 40 41 - 50 > 50 don expass	
12. What is the recipient's blood typ 1	legative Negative Negative		
 13. Has the recipient ever been pres 1 □ yes> 2 □ no 	gnant? EVERPREC; 14. Number of pregnancies:	NUMPRES	
 3 □ not known 4 □ not applicable, recipient is was the functional status of 		ning? XPS	
4 I not applicable, recipient is was the functional status of	If the recipient prior to condition der, complete the Karnofsky Scale. If	the recipient is younger than 16 years of age, complete the Lansky Scale.	
4 not applicable, recipient is was the functional status of the property of th	of the recipient prior to condition der, complete the Karnofsky Scale. If prior to initiation of conditioning.	· · · · · ·	
4 I not applicable, recipient is was the functional status of recipient is 16 years of age or of Rate activity of recipients immediately KARNOFSKY S Check the phrase in the Karno	of the recipient prior to condition der, complete the Karnofsky Scale. If prior to initiation of conditioning. CALE ≥ 16 yrs (sky Scale which best	the recipient is younger than 16 years of age, complete the Lansky Scale. LANSKY SCALE < 16 yrs	·
4	of the recipient prior to condition der, complete the Karnofsky Scale. If prior to initiation of conditioning. CALE ≥ 16 yrs (sky Scale which best the recipient: ity; no special care is no evidence of disease mal activity effort	the recipient is younger than 16 years of age, complete the Lansky Scale.	

NMDP Form 120, 520, 620 V7 (5-13) November 1998

□ 20 Very sick; hospitalization necessary
 10 □ 10 Moribund; fatal process progressing rapidly

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Recipient				
NMDP ID		-		

٦	Recipient		T	 		<u> </u>	Γ	[[
]-	Last Name:	L				L	L				

ere there clinically significant coexisting diseases (e.g., diabetes mellitus) or organ impairment within one month prior to

1 🛛 yes	Indicate the diagnoses:	DXI20X20
2 D no DXSIGHEM	17. 1 🗆 yes 2 🗆 no	Significant hemorrhage (e.g., CNS or GI), specify site(s):
DXCORART		Coronary artery disease
DXHYPERT		Hypertension
DXOTCARD		Other cardiac disease, specify:
DXDIAMEL		Diabetes mellitus
DXTHYDIS		Thyroid disease
OXOTENDO	23. 1 🗆 yes 2 🗆 no	Other endocrine disease, specify:
DXSETEUR	24. 1 🛛 yes 2 🖾 no	Seizure disorder
DXOTHONS	25. 1 🗆 yes 2 🗖 no	Other CNS disease, specify:
÷	r 26. 1 □ yes 2 □ no	Asthma
DXPULMON	27. 1 🛛 yes 2 🗖 no	Pulmonary disease, specify:
DXGENITO	28. 1 🗆 yes 2 🗖 no	Genitourinary disease, specify:
· DXGASTRO		Gastrointestinal disease, specify:
DXHEMATO	30. 1 🛛 yes 2 🖾 no	Hematologic disease, specify:
DXFANCON	31. 1 🗆 yes 2 🗆 no	Fanconi anemia
DXDOWNSY	32. 1 🗆 yes 🔤 2 🗖 no	Down syndrome
DXOTCHRO	33. 1 🗆 yes 2 🗆 no	Other chromosomal disorders, specify:
DX OTMALI	34. 1 🗆 yes 2 🗆 no	History of other malignancy, specify:
DXNEOGNH	35. 1 🗆 yes 2 🗆 no	Neonatal GVHD
DXOTHER	36. 1 🗆 yes 2 🗆 no	Other, specify:

Organ Function Prior To Conditioning

Provide values for recipient's liver function just prior to conditioning:

•		..		What is the upper	limit of
		Date tes	ted:	normal for your ins	
XoSGIQ		Month Day	Year		_
37. AST (SGOT)	U/L SGOTAT38.			39.	ULXSGOTULN
40. ALT (SGPT)	U/L Unit of 41.				U/L Unit of
43. Total serum bilirubin	• _ 2 _ µmol/L			45.	
46. LDH	U/L 47.			48.	
		LDHDT		LDHULN	
49. Did the recipient have I	known clinical liver disease (e.	q., hepatitis) at any ti	me prior to condit	ioning? / LVED P	1 1 40
1 🗆 yes>		g., nopenilo, at any in		LIVERL	1/3
	50. Specify:			·····	
2 🗆 no	51. Date of onset:	·Month Day	Year	LIVDISDT	
52 ** that was the recipient	's serum creatinine prior to cor	nditioning?		•	
	Unit of measure Unit of measure 1 I mg/dL CF.VM		3. Date tested:	Month Day	Year
NMDP Form 120, 520, 620 V7 Copyright © 1998 National Ma		erved.		CRBT	

Recipient NMDP ID:	Recipient Last Name:
ig for serologic	al evidence of prior viral exposure / infection
 65. Hepatitis B surface ant 66. Hepatitis C antibody <i>f</i> 67. Hepatitis A antibody <i>f</i> 68. HIV 5 □ confidentia 69. Other, specify <u>D174</u><i>P</i> 70. Was the recipient treate 1 □ yes 	body CNV 1 positive 2 negative 3 inconclusive 4 not tested EPSTBARA 1 positive 2 negative 3 inconclusive 4 not tested A/or core antibody HEPB/DDPpositive 2 negative 3 inconclusive 4 not tested A/or core antibody HEPB/DDPpositive 2 negative 3 inconclusive 4 not tested A/or core antibody HEPB/DDPpositive 2 negative 3 inconclusive 4 not tested A/or core antibody HEPB/DDPpositive 2 negative 3 inconclusive 4 not tested A/or core antibody HEPB/DDPpositive 2 negative 3 inconclusive 4 not tested HEPC BODY 1 positive 2 negative 3 inconclusive 4 not tested HEPCGEN 1 positive 2 negative 3 inconclusive 4 not tested A/HV 1 positive 2 negative 3 inconclusive 4 not
2 🗖 no	1 Conventional private room 4 Positive pressure room 2 Laminar air flow room 5 HEPA filtered plus positive pressure room 3 HEPA filtered room 6 Other, specify:
74. Weight at initiation of pre	itioning began: Month Day Year transplant conditioning (nearest centimeter without shoes): etransplant conditioning (nearest kilogram without shoes): d as part of the pretransplant preparative regimen? PORTYPAN
2 🗆 no	76. Source of X-ray therapy: 1 □ Linear accelerator 2 □ •Co XRAVSRCE
Cont. with 111	 77. Calculated dose-rate during irradiation: cGy (rad)/min XRAYPATE 78. What was the radiation field? PADFIELS 1 □ Total body 79. Total dose: cGy RFTOT 005 80. Starting date: CGy RFTOT 005 80. Starting date: RFAT 81. Was radiation fractionated? RFFRAC VN 1 □ yes 82. Dose per fraction: cGy 83. Number of days: RFDAYS
NMDP Form 120, 520, 620 V7 (8 November 1998 Copyright © 199 Marrow Donor Program. All rights	 At. Total number of fractions: Bt. Was shielding used? 1 □ yes 2 □ no 13) 5 National 84. Total number of fractions: 86. Indicate which organs were shielded: a. Lungs RFSHLUNG: b. Eyes AFSHENG: c. Liver Righting Uses □ no d. Kidney PFSHLUNG: yes □ no yes □ no d. Kidney PFSHLUNG:



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Recipient NMDP ID:		Recipient Last Name:	
	• •		
*			

H compatibility Tests

For each of the following tests indicate whether it was a basis for matching the donor to the recipient:

126.	Class I HLA Serology	CLISIHLA	1	matched	2 🛛 mismatched	3 🛛 not done
127.	Mixed Lymphocyte Culture (MLC)	MLC	1	matched	2 🛛 mismatched	3 🔲 not done
128.	Restriction Fragment Length Polymorphism (RFL	P) RFLP	1	matched	2 D mismatched	3 🛛 not done
129.	Isoelectric Focusing (IEF)	TEF	1	matched	2 🗖 mismatched	3 🛛 not done
130.	Cytotoxic Lymphocyte Precursors (CTLP)	OTLP	1	matched	2 d mismatched	3 🛛 not done
131.	Helper T Lymphocyte Precursors (HTLP)	HTLP	1	D matched	2 🛛 mismatched	3 🛛 not done
132.	Class I Sequence Specific Oligo Probe (Class I S	SOP) SSOPI	1	matched	2 🛛 mismatched	3 🛛 not done
133.	Class II Sequence Specific Oligo Probe (Class II S	SSOP) SSOPII	1	matched	2 🛛 mismatched	3 🗖 not done
134.	Other, specify:		1	matched	2 🗖 mismatched	3 🛛 not done

Transplant Maneuver

Questions 135-158 are for marrow only. For peripheral blood stem cells, continue with question 159 and complete Form 580. For cord blood, continue with question 159 and complete Form 680.

135.	Copy donor reference i	number from specimen here:	DONREFNO
136.	Date of receipt of marro	ow at your facility:.	Month Day Year
137.	Time (24-hour clock) at	t receipt of marrow: MARLECTM	Hour Hour Minute 1 I standard time MARECZN
13u.:	storage temperature du	uring transport: STORTEMP	1 C Refrigerated at 1–8°C 2 Room temperature
139.	Nucleated cell count of processing (uncorrected	the marrow before Bag one: d cell count):NCCB@FB1	• x 10°/mi Bag • x 10°/mi •
		NCCBEFB3 three	• x 10°/ml Bag • NCCBEFB4
140.	Method used to determ	ine nucleated cell count: NCCMETH	1 □ Coulter counter 2 □ Manual count 3 □ Other, specify:
141.	Total volume of marrow	before processing:	. VOLBEFOR
142.	Was the marrow manip	ulated at your facility prior to tra	ansplant?
	1 yes ANTRYN	143. Was the marrow manipu	ulated for volume reduction only? 1 U yes 2 D no MANVRONI
		144. Was the marrow plasma	
	Ļ	145. Was the marrow manipu	alated for ABO incompatibility only? 1 I yes 2 I no MANABO
1	Cont. with 150		Ilated for GVHD prophylaxis?
		$\frac{1}{2} \bigcirc \frac{1}{2} \odot \frac{1}{2} \bigcirc \frac{1}{2} \bigcirc \frac{1}{2} \odot \frac{1}{2} \bigcirc \frac{1}{2} \odot \frac{1}{2} \bigcirc \frac{1}{2} \odot \frac{1}{2} \bigcirc \frac{1}{2} \odot \frac{1}$	 147. Specify method used: MANMETH 1 □ Antibody + complement 2 □ Antibody + toxin 3 □ Antibody affinity column 4 □ Soybean lectin only 5 □ Sheep red blood cell rosetting only
			6 Soybean lectin and sheep red blood cell rosetting
			7 🗆 Elutriation
			8 🗇 Immunomagnetic beads
			9 Antibody coated plates
Noven	P Form 120, 520, 620 V7 (1 nber 1998 Copyright © 199	11-13) 98 National	10 Soybean lectin and antibody coated plates
	w Donor Program. All right		11 Other, specify:
	1	í	1 8

Recipient NMDP ID:	- Recipient Last Name:
	 148. If antibodies were used during marrow manipulation, indicate which antibodies were used: a. anti CD2 ANTICO2 1 □ yes 2 □ no b. anti CD3 3 1 □ yes 2 □ no c. anti CD4 4 1 □ yes 2 □ no d. anti CD5 5 1 □ yes 2 □ no e. anti CD6 6 1 □ yes 2 □ no f. anti CD7 7 1 □ yes 2 □ no g. anti CD8 6 1 □ yes 2 □ no h. anti CD34 34 1 □ yes 2 □ no h. anti CD34 34 1 □ yes 2 □ no i. Other 99 1 □ yes 2 □ no j. No antibodies used □ ANTINONE 149. What assays were performed to determine the number of T-cells left in the marrow after processing? a. Flow cytometry 1 □ yes 2 □ no b. Limiting dilution assay 1 □ yes 2 □ no c. Other 97 1 □ yes 2 □ no b. Limiting dilution assay 1 □ yes 2 □ no c. Other 97 1 □ yes 2 □ no b. Limiting dilution assay 1 □ yes 2 □ no c. Other 97 1 □ yes 2 □ no b. Limiting dilution assay 1 □ yes 2 □ no c. Other 97 1 □ yes 2 □ no b. Limiting dilution assay 1 □ yes 2 □ no c. Other 97 1 □ yes 2 □ no b. Limiting dilution assay 1 □ yes 2 □ no b. Limiting dilution assay 1 □ yes 2 □ no b. Limiting dilution assay 1 □ yes 2 □ no c. Other 97 1 □ Yes 2 □ no d. Not done □ NO ASSAYS
150. Time (24-hour cloo	k) at start of infusion: TXTIME Hour: Minute 1 I standard time TX ZONE
1.5 tal volume of ma	irrow infused on the day of transplant:
152. Cell count of infus	ed marrow (uncorrected cell count):
153. Method used to de	termine cell count: 2
154. Was a fraction of t	ne collected marrow cryopreserved for back-up infusion?
1 🖸 yes 2 🖾 no	155. Total volume of cryopreserved marrow: .
CRYOYN	155. Total volume of cryopreserved marrow: • ml. CRYOVOL 156. Nucleated cell count of cryopreserved marrow: • • CRYONCC
157. Was there any adv	erse reaction associated with the infusion?
1 🗆 yes	► 158. Specify:
ADVERSE:	.
)	

٠

Recipient NMDP ID:	- Last Name:
/	asplant for this recipient?
1 🛛 yes 2 🖓 no	160. What was (were) the prior stem cell source(s)?
FIRSTIX	a. Autologous AUTOLOG
	1 □ yes → 161. a. Bone marrow AUTBM 1 □ yes 2 □ no 2 □ no b. Peripheral blood AUTBM 1 □ yes 2 □ no
	b. Allogeneic, unrelated ALLOGUNR
	1 U yes 162. a. Bone marrow ALUBM 1 U yes 2 0 no
	2 □ no b. Peripheral blood ALUPB 1 □ yes 2 □ no c. Cord blood ALUCB 1 □ yes 2 □ no
	c. Allogeneic, related
	1 u yes
	ALWGREL b. Peripheral blood 1 ges 2 no C. Cord blood 1 ges 2 no
	164. Date of the last transplant (transplant just before current transplant):
	PREORDT Month Day Year
	165. Reason for <i>current</i> transplant:
	1 D No engraftment REASON TX 2 D Partial engraftment
	3 Graft failure/rejection 4 D Persistent malignancy
	5 CRecurrent malignancy
	6 Other, specify:
	166. Source of stem cells for current transplant: CEUSRCE 1 □ Autologous
	1 □ Cryopreserved bone marrow 2 □ Cryopreserved peripheral blood stem cells CEUSCTP
	2 Allogeneic, unrelated
	 Fresh, original donor bone marrow Cryopreserved original donor bone marrow
	 3 Fresh, second donor bone marrow 4 Fresh, original donor mobilized peripheral blood stem cells
	5 Cryopreserved original donor mobilized peripheral blood stem cells
	 6 Fresh, second donor mobilized peripheral blood stem cells 7 I NMDP cord blood
	8 INON-NMDP cord blood 3 Allogeneic, related
	1 D Bone marrow
•	2 Peripheral blood 3 Cord blood
57 Signed	
-	Person completing form
-	`
	(42, 40) November 4000

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National Marrow Donor Program®	10191DT-121	
Insert I – Acute Myelogenous	Unrelated Recipient	
Leukemia		
Leukenna	Recipient Last Name:	
Ϋ́,		
	Recipient Local ID (optional):	
Registry Use Only		
	Today's Date: TC Co	de:
Sequence	Month Day Year	
Number:	Date of Transplant for which this form	
Data	is being completed:	Year
Date Received:	Product type: A Marrow PBSC Cord blood	
	(Form 120) (Form 520) (Form 620)	
	ter en	
This form must be accompanied by Form 120	0, 520, 620 – Recipient Baseline and Transplant Data. All	information in
	identical with the corresponding Form 120, 520, 620. In	
	the Transplant Center physician, or the physician who is	s following the
recipient post-transplant, or abstraction of th	e recipient's medical records.	
1. What was the date of diagnosis of Acute Myeloge	enous Leukemia?	LDT
· · · · · · · · · · · · · · · · · · ·	Month Day Year	
2. Was this a secondary (therapy-linked) leukemia?		
1 ges	(malignant or nonmalignant):	
1 L Hodgkin lympt		
SECOLENK 2 Non-Hodgkin	ymphoma	
3 🗖 Other, specify:		
4. What was the date	of diagnosis of prior disease?	ISPRIDT
5. Treatment for prior		
a. Radiation	1 yes 2 no TRTRADIA	
b. Chemotherapy		
TRIDINYN c. Other	1 yes 2 no If yes, specify:	
d. Unknown	1 🗍 yes 2 🗋 no	
5. Did the recipient have a documented antecedent	hematologic disorder (preleukemia or myelodysplastic syndrom	ie)?
1 🖸 yes		
2 no AHDISOLD 7. What was the date	of diagnosis of antecedent hematologic disorder?	
	AHDIAG DT Month	Year
8. What was the class	ification of hematologic disorder at diagnosis? (complete Form	1 120, Insert V)
Cont. with 11 1 Refractory ane		
	mia with excess blasts (RAEB)	
	mia with excess blasts in transformation (RAEBT)	
	monocytic leukemia (CMML)	
	athic sideroblastic anemia	
	ctumal hemoglobinuria (PNH)	
8 🗆 Essential throm		
	vith myeloid metaplasia	
	rosis or myelosclerosis	
12 D Acquired aplas	splasia or myeloproliferative disorder, specify:	
12 L Acquired aplas		- -
)]

Mail to NMDP Registry with Form 120, 520, 620. Retain a copy at the transplant center.

Recipient IMDP ID:		st Name:					
CYAAMLYN	Did recipient have a cyto 1	genetic abnormality What was (were) t a. Monosomy 7 b. Trisomy 8 c. 5q- d. Other	he cytogentic abnor	the course of the c mality(ies)? MON0S07 TR1508 FINEQ If yes, specify:	lisease?		
1. Did recipient have a predispo 1 ges 12 2 no 12. PDCAMLYN PDCAMLOT -		diagnosis of leuken PDCAMLFA PDCAMLBS PDCAMLDS					
lematologic Findings at	Diagnosis of Acute	Myelogenous	Leukemia				
3. WBC: 1	BCAML × 10°/L	10 ³ /mm ³					
 4. Blasts in blood: 1 □ known [2 □ not known 	BBAML %						
 5. in bone marrow: 2 not known 6. Was extramedullary disease p 	BBMAML						
	Please specify sites: a. Central nervous system b. Other EMDAMLO	1 ∐ yes 2 ∐ n 7 1 ∐ yes 2 ∐ n	o EMDAMLa o If yes, specify: _	CN			
 8. Were cytogenetics tested at diagnosis, prior to start of treatment? CYAMLTST 1 yes 2 yes, but no evaluable metaphases 3 no 4 unknown CYAMLTST 1 yes 2 no 3 no 4 unknown CYAMLTST 2 no 3 no 2 no 3 no 3 no 4 no _							
2. Was a first complete remission 1 up yes 7 FRAMLYN 23.	n achieved? Date:	Year	FRAMLDT				
Cont. with 29					J		

•

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Recipient NMOP ID:	- Recipient Last Name:									
24 a relapse occur pretr	ransplant?									
yes	25. Date of first relapse:									
REPLAMLYN	Month Day Year 26. Did the first relapse occur on chemotherapy? 1 🗆 yes 2 🗆 no RELAMLCH									
	27. Was additional therapy given after the first relapse?									
	28. Indicate what therapy was given:									
	2 ID no a. Chemotherapy 1 ID yes 2 ID no THAMLCHM RELAMLTH b. Radiation 1 ID yes 2 ID no THAMLRAD									
	c. Surgery 1 U yes 2 0 no THAMLERG d. Immunotherapy 1 U yes 2 0 no THAMLEMM									
	d. Immunotherapy 1 □ yes 2 □ no ¬¬¬A¬M∟⊤MM e. Other 1 □ yes 2 □ no If yes, specify:									
	THAMLOTH									
L										
	rimary disease immediately prior to conditioning of recipient for transplant? STATAML									
•	ilure Cont. with 31									
	sion (no previous marrow or extramedullary relapse)									
3 🗆 2nd CR	-									
4 🖸 3rd CR										
5 □ ≥ 4th CR										
	1 medullary 2 extramedullary 3 both									
2nd relapse	1 medullary 2 extramedullary 3 both									
i0. What was the initial date t	this disease status was achieved?									
lematologic Findings	Just Prior to Conditioning									
1. WBC:	$\square \cdot \square \times 10^{9/L} (or 10^3/mm^3) \text{WBCAMLIN}$									
2. Blasts in blood:	D. & BLBAMLIN									
3. Blasts in bone marrow:	• % 34. Date of bone marrow examination:									
t	BLMAMLIN Month Day Year									
Continue with question	10 on page 5 of the Form 120, 520, 620. BMAML DT									

	NMBY 221								
Insert II – Acute Lymphoblastic	Unrelated ID Recipient								
Leukemia	Recipient Last Name:								
	Recipient Local ID (optional):								
Registry Use Only	NA22DT Today's Date: TC Code: TC Code:								
Sequence Number:	Month Day Year Date of Transplant for which this form								
Date Received:	is being completed: Month Day Year Product type: Marrow PBSC Cord blood (Form 120) (Form 520) (Form 620)								
This form must be accompanied by Form 120, 520, 620 – Recipient Baseline and Transplant Data. All information in the box above, including the date, should be identical with the corresponding Form 120, 520, 620. Information should come from an actual examination by the Transplant Center physician, or the physician who is following the recipient post-transplant, or abstraction of the recipient's medical records.									
1. What was the date of diagnosis of Acute Lymphot	blastic Leukemia?								
2. Did recipient have a predisposing condition prior	to the diagnosis of leukemia?								
PDCALLYN 2 Bloom syndro 3 Down syndror	nia PDCALLEA mePDCALLBS ne PDCALLDS : <u>PDCALLOT</u>								
Hematologic Findings at Diagnosis of A	Acute Lymphoblastic Leukemia								
4. WBC: 1 □ known →	0% WBCALL								
5. Blasts in blood: 1 known 2 not known	BBALL								
6. Blasts in bone marrow: 1 □ known →	BBMALL								
7. Was extramedullary disease present at diagnosis	s?								
71 □ yes 8. Please specify site 2 □ no a. CNS EMDA EMDALLYN b. Testes EMDA c. Mediastinum EN d. Other site(s) EN	ALLCN 1 Uyes 2 0 no 3 0 unknown ALLTE 1 Uyes 2 0 no 3 0 unknown MDALLME Uyes 2 0 no 3 0 unknown MDALLOT 1 Uyes 2 0 no 3 0 unknown								
)	If yes, specify:								

Recipient NMDP ID: /ere cytogenetics teste 	ed at diagnosis, prior to sta 10. Number of metapha 11. Was karyotype norm 2 □ no KNALLYN	ses examined: META nal? 12. Specify the abnormal a. Hyperdiploid	ity(ies): 1	2 □ no k 2 □ no k 2 □ no k 2 □ no k 2 □ no k	AALL AALL	-92 -92 -814 -141 -141	0 2 F
13. Was a first complete rer	r						
2 no FRALLYN	14. Date: Month	Day Year F	RALL	DT			
Cont. with 20						<u></u>	
15. Did a relapse (marrow o	r extramedullary) occur pro	etransplant?	· · · · ·			· · · · ·	
RELALLYN	16. Date of first relapse:	Month Day	Year	REL	ALLD-	T	
, -	17. Did the first relapse of		1 🛛 yes 2	no Re	ELALL	-CH	
		py given after the first relap					
	RELALLTH	19. Indicate what therapy a. Chemotherapy	-	2 🗖 no 🏋	LALI	CHI	M
•	RELALLTH	b. Radiation	-		TIALL		
		c. Surgery	1 🛛 yes	2 🗖 no 🕆	-+++	L SR	Ġ
		d. Immunotherapy	1 🛛 yes				
		e. Other	1 □ yes		HAL	LOT	4
			If yes, spec	;;]
20. What was the status of p	primary disease just prior to	conditioning of recipient fr	or transpiant	2			
	ailure	• · ·		••			
		or extramedullary relapse)				•	
₹ / 3 □ 2nd CR							
F 4 □ 3rd CR							
$\begin{array}{c c c c c c c c c c c c c c c c c c c $		•					
φ	> 1		tramedullary	, <u>3</u> [J both	STAT	TALL?
[▶] □ ≥ 2nd relapse		🗆 medullary 2 🗆 ex	tramedullary	/ 3[] both	ς τ τ	

Day

Month

Year

STTALLDT

21. What was the initial date of this disease status?

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Recipient - C		Recipient Last Name:												
		.									•			
atologic Finding	s Just Prior to Cond	litioning												
22. WBC:	• × 109/L	WBCAL	LIN											
23. Blasts in blood:	. % BL	BALLIN	-											
24. Blasts in bone marrow:	<u> </u> . % →	- 25. Date of b	one mar	TOW 6	examin	ation:][][
	BLMALLIN						MC C	ŠN	14	Day	D	Т	Year	
Continue with question	10 on page 5 of Form 12	20, 520, 620.												

ŗ
		MUXIAO
National Marrow Donor Program® Insert III – Chronic Myelogenous	Unrelated	NMDP ID: -
Leukemia (CML)	Recipient Last Name:	
	Recipient Local ID (optional	ıl):
Registry Use Only	NA23DT Today's Date:	TCCODE TC Code:
Sequence Number:	Month	Day Year
	Date of Transplant for which is being completed:	Month Day Year
Date Received:	Product type: D Marrow (Form 120)	· · · · · ·
the box above, including the date, should	be identical with the correspo by the Transplant Center phys	sician, or the physician who is following the
1. What was the date of diagnosis of Chronic	Ayelogenous Leukemia?	Day Year CMLDT
Hematologic Findings at Diagnosis	of Chronic Myelogenous	Leukemia
2. Hemoglobin (only recipients untransfused w	thin 4 weeks):	• g/dL unknown HGBCM
3. Hematocrit (only recipients untransfused wit	nin 4 weeks):	• wunknown HCTCM
atelets (only recipients untransfused within	4 weeks):	• x 10% Junknown PLTCM
5. WBC:		• x 10%L unknown WBCCM
6. Eosinophils:		• % unknown EOSCML
7. Basophils:		• % Unknown BASCML
8. Blasts:		• □ % □ unknown BASCML • □ % □ unknown BLSCML • □ %
9. Did the recipient receive a splenectomy?		
1 □ yes 10. Date: 2 □ no 10. Date: SPLENCML Mc		SPLCMLDT
11. Did the recipient receive chemo- or immuno-	therapy at any time prior to pre-tra	ansplant conditioning?
71 🗆 yes	drugs used:	
CHEMIMMT	1 Uyes 2 D no BUSL	ILFAN
	a 1⊡yes 2⊡no HYD pha 1⊡yes 2⊡no Ain	ROXYU
d. Interferon g	pha 1 🗆 yes 2 🗆 no ALP amma 1 🗆 yes 2 🗆 no GAN	MAINT
e. Anegrilide	1 Uyes 20 no ANE	GRILI
f. Other drug	1 yes 2 no OTH	ICIVN

If yes, specify:

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Recip NMDF		- Recij Last	Name:
	/		
	hat was the status of the prin	ary disease just prior to o	conditioning of recipient for transplant?
in the second	First chronic phase	Cont. with 20	
2	Accelerated phase	14. Was this the first	accelerated phase?
		1 🗆 yes 2 🗆 no	FIRSTACC
		15. Indicate which of	the following were present:
			Anemia (hemoglobin < 8 g/dL) ANEMIA
and the second se		1 🗆 yes 2 🗆 no	Leukocytosis (WBC > 10^{5} /mm ³) unresponsive to busulfan or hydroxyurea LEUKOCYT
		1 🗌 yes 2 🗋 no	Thrombocytopenia (platelets < 10 ⁵ /mm ³) unresponsive to busulfan or hydroxyurea THROMBLO
		1 🗆 yes 2 🗆 no	Thrombocytosis (platelets > 10 ⁶ /mm ³) unresponsive to busulfan or hydroxyurea THROMBHT.
	*	1 🗆 yes 2 🗆 no	Palpable splenomegaly unresponsive to busulfan or hydroxyurea
		1	Development of extramedullary disease DEVEMDIS
2			≥ 10% Blasts in blood or marrow BLASTS10
S)		≥ 20% Blasts plus promyelocytes in blood or marrow BLASTS20
F	58 		≥ 20% Basophils plus eosinophiles in blood BASOPH20 Clonal marrow cytogenetic abnormality(ies) in addition to the
IN JELS	ka		single Philadelphia chromosome arising from the standard t(9;22) translocation $CMCVTABN$
V		1 🗆 yes 2 🗆 no	Other, specify: ACCOTHYN
	1	Cont. with 20	
`. ъ г	Blastic phase	16 How many blast o	rises has the recipient ever experienced?
			or more BLSTCR 5
1		17. Indicate type of bl	
Į		J /1 D Lymphoid onl	
1	ĺ	J / 2 □ Myeloid only 3 □ Lymphoid and	
	Č		-
	Ę) `	eterminate results)
		Cont. with 20	
₄⊡	Second or greater	18. How many chronic	phases has the recipient experienced?
	chronic phase (for those recipients who have not	1 Two	
	had a previous BMT)	2 Three 3 Four or more	
		$ \begin{array}{c c} 1 & \square & Two \\ 2 & \square & Three \\ 3 & \square & Four or more \\ \hline Cont. with 20 \end{array} $	
50	Chronic phase	19. Please specify:	
X		First chronic p	
		$2 \square \ge$ Second chro	onic phase post BMT
	Криту	Cont. with 20	
		L	

Recipient NMDP ID:		-[-		
-----------------------	--	----	--	--	---	--	--

Recipient	
Last Name:	

g/dL

x 10⁹/L

x 10⁹/L

%

%

%

%

•

•

٠

hin Four Weeks Prior to Conditioning

ن لن كid recipient receive red blood cell transfusions within four weeks prior to conditioning?

1 yes RBCTRANS

- 21. Did recipient receive platelet transfusions within four weeks prior to conditioning?
 - 1 ves 2 no PLTTRANS

Peripheral Blood Findings Immediately Prior to Conditioning

- 22. Hemoglobin (only recipients untransfused within 4 weeks):
- 23. Hematocrit (only recipients untransfused within 4 weeks):
- 24. Platelets (only recipients untransfused within 4 weeks):
- 25. WBC:
- 26. Eosinophils:
- 27. Basophils:
- 28. Blasts:

Most Recent Bone Marrow Findings

The of the most recent bone marrow examination prior to conditioning (Should be hin 30 days of conditioning but not more than six months prior to conditioning):

30. Indicate the percent of blasts and promyelocytes present according to the laboratory's reporting method:

a. D Blasts: % BM/HROMVE %	
b. □ Blasts plus promyelocytes: ● ● % BMBLPROM	
c. □ Blasts plus promyelocytes < 5% BMBLPRØ5	
31. Myelofibrosis: 1 absent 2 mild 3 moderate 4 severe 5 unknown	
 32. Was Philadelphia chromosome (9;22 translocation or variant) present? 1 □ yes 2 □ no 3 □ not tested 	
33. Was other cytogenetic abnormality present?	
1 ges 34. Please specify: 2 no CYACMLYN 34. Please specify:	
35. Was BCR-ABL rearranged?	
Continue with question 10 on page 5 of Form 120, 520, 620	

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□ not done HGBCMLIN

□ not done + CTCMLIN

I not done PLTCMLIN

□ not done WBC CMLIN

not done EOSCMLIN

D not done BASCMLIN

□ not done BLSCMLIN

100-Day Follow-Up Visit of	Unrelated Recipient NMDP ID:
Recipient WMDP130	Recipient Last Name:
	Related Unique Recipient Number (UPN):
Registry Use Only	Unrelated Recipient Local and Related ID (optional):
Sequence Number	Today's Date: Month Day Year TC Code:
Date Received.	Date of Transplant for which this form is being completed:
	Product type: American PBSC Cord blood

Unrelated Donor Marrow Transplant and Related Donor Marrow Transplant for CML Recipient

who is following the re	me from an actual examination by the transplant center physician, or the private physician ecipient post-transplant. Research blood samples from recipients receiving marrow from and be collected and sent to Blood Centers of the Pacific, Irwin Center. See Manual of I instructions.
	with recipient to determine medical status for this follow-up report:
 Did recipient receive a day 100 after the trans 	subsequent stem cell infusion (bone marrow, mobilized peripheral blood stem cells, cord blood) prior to plant for which this form is being completed? STEMCULS
yes>	Answers to subsequent questions should reflect clinical status immediately prior to start of conditioning for subsequent stem cell infusion. Be sure to answer questions 167–169 on page 18.
	o day 100 after the transplant for which this form is being completed? DIED3
1 🗆 yes	Answers to subsequent questions should reflect clinical status immediately prior to death.
2 🔲 no	Answers to subsequent questions should reflect clinical status on day of actual contact for this follow-up evaluation (approximately 100 days post-transplant).
4. Has recipient received	an infusion of peripheral blood mononuclear cells or lymphocytes from the original donor? PBMC DP \gtrsim
1 🗆 yes	5. Date the first infusion was given:
	6. Recipient weight within 2 weeks of first infusion: kg PBMCWT3
	7. Total number of infusions:
	8. Total dose of mononuclear cells: • × 1010 PBMCMNC3
	 9. Indication for the infusion(s) of donor cells: PBMCIND3 1 □ Relapse 2 □ Treatment for B cell lymphoproliferative disorder 3 □ Prophylaxis against B cell lymphoproliferative disorder 4 □ Graft failure 5 □ Viral infection, specify:
	6 🗆 Other, specify:



NMDP Form 130, 530,630 V8 (2-18) November 1998

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Recipient		Recipient Last Name:
Gr opoiesis	of hematopoietic recovery	HEMREC3- following the initial bone marrow infusion? (Check only one)
1 ☐ Yes. ANC ≥ 500/mm ³ achieved and sustained for 3 consecutive lab values with no subsequent decline	taken on different day	n ³ achieved and sustained for 3 consecutive lab values taken on different
2 \Box Yes, ANC \geq 500/mm ³ for 3 consecutive lab values with		(first of 3 consecutive days): ANCYUYN 3 ANCYUYN 3 A
subsequent decline in ANC to < 500/mm ³	1 🗆 yes	Date (first of 3 consecutive days): ANCYUDI3 Month Day Year
for greater than 3 days	ANCYD	
)	Actual CBC on first day of 19. WBC:	decline:
	20. Neutrophils: 21. Lymphocytes:	I. MANCINEUS I. MANCLYMS
	22. Did recipient recover a 1 ges 2 no Continue with 27	and maintain ANC \geq 500/mm ³ following the decline? ANCYRYN3 23. Date of ANC recovery: ANCYRDT3 Month Day Year Actual CBC on first day of recovery:
		24. WBC: X 10 ¹ /L ANCRWBC3 25. Neutrophils: 0% ANCRNEU3 26. Lymphocytes: 0% ANCRUM3
3 □ No, ANC ≥ 500/mm there was no evider in the bone marrow	nce of recurrent disease	Continue with 27
	was not achieved and ted persistent disease post-transplant	Continue with 68

Recipier NMDP I	
2-	<pre>spected etiology of failure to achieve ANC > 500/mm³ or a decline in ANC: A NCPDR3 Persistent disease or relapse 1 yes 2 no Immune mediated rejection ANCIM3X 1 yes 28. Immune mediated etiology: ANCIM31 2 no 28. Immune mediated etiology: ANCIM31 20. no 29. 10. yes 2 no 20. yes</pre>
C.	Graft versus host disease 1 D yes ANCGUHDB 2 D no
	Non-viral infection 1 U yes ANCNVI3 2 U no
e.	Suspected viral infection 1 yes
f.	Documented viral infection ANC DV 3X(
	Antimicrobial therapy ANCAMBY 1 yes

Megakaryopoiesis

The following questions relate to *initial* platelet recovery. All dates should reflect no transfusions in previous 7 days, and the first of 3 consecutive laboratory values.

32. Was a platelet count of	20.000 achieved? PL	124N3	
1 🗆 yes	33. Date platelets ≥ 20,000:	Month Day Year PLIZDT3	
2 🗆 no	Continue with 38		ل

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Recipient	Recipient Last Name:
3 s a platelet count of \geq 50,000 achiev	red? PLISTN3
1 🗆 yes — 35. Date plate	lets ≥ 50,000: Month Day Year PLISDT3
2 D no Continue with	38
36. Was a platelet count of \geq 100.000 achie	
1 🗍 yes — 37. Date plate	
2 no Continue with	38
38. Was recipient ever platelet transfusion i	ndependent? PLITIYN3
	of the last platelet transfusion known?
1 🗋 ye 2 🗌 no	S PLITIKIN3
required plate	s platelet transfusion independent for \geq 14 days and then subsequently expenenced a decline in platelet count and et transfusions, record date of last platelet transfusion <i>before decline in counts</i> . If recipient has not required platelet ince initial platelet recovery, record date of last platelet transfusion.
2 D no Continue with	51
40. After initial recovery to platelet count ≥ 2 decline to < 20,000 for one laboratory v	20,000 did the platelet count decline to < 20,000 for 3 consecutive laboratory values or a alue and the recipient received a platelet transfusion? $PLTTIDTS$
1 🖸 yes — 41. Date of the	e first day platelet count declined below 20,000:
	t count recover? PL) PLANE Month Day Year
1 🗆 ye 2 🗖 no	Continue with 43 Continue with 49
2 D no Continue with	
The following date questions relate to subset	quent platelet recovery following a decline of platelet count to below 20,000. All dates
	lays, and the first of 3 consecutive laboratory values.
43. Was a platelet count of ≥ 20.000 achiev 1 □ yes	
	Month Day Year
2 no Continue with	
45. Was a platelet count of ≥ 50,000 achiev	
46. Date plate	ets ≥ 50,000: PLSSDT3 Month Day Year
2 🔲 no ———— Continue with	49
47. Was a platelet count of <u>> 100,000 achie</u>	ived? PLSIOYNS
1 □ yes 48. Date platei	Nets ≥ 100,000: Day Year PLSIDDT3
49. Is recipient now receiving platelet transl	
1 🗆 yes Continue with	51 PLSREC3
	of the last platelet transfusion known? PLSKNWN 3
1 🗆 ye 2 🗔 no	
If platelet cour	t ≥ 100.000 achieved, continue with question 56. Otherwise continue with question 51.

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•	spected etiology of failure to achieve a platelet count ≥ 100,000 or decline in platelet count to < 20,000:
<i>ۇ</i> . ق ى	Persistent disease or relapse 1 yes 2 no
ь	Immune mediated rejection PLTIM 3×5
0	
	52. Immune mediated etiology. PC(12M/3)
	a. 1 Dyes 2 D no Cellular PLTIM32 b. 1 Dyes 2 D no Antibody PLTIM33
	c. 1 U yes 2 U no Third party engraftment PCTIM34
	d. 1 🗆 yes 2 🗆 no Unknown PLTIM 35
-	Graft versus host disease
С	
	$\frac{1}{2} \frac{1}{10} $
-	Non-viral infection
۵	
	20 no PLTNUIS
	Suspected viral infection PLTSU376
e.	
	a. 1 U yes 2 D no Cytomegalovirus (CMV) PLTSV32 b. 1 U yes 2 D no Human Herpesvirus Type 6 (HHV6) PLTSV33
	c. 1 ges 2 no Herpes Simplex Virus (HSV) PLTSV34
	d. 1 ves 2 no Varicella ALTSU34 PLTSU35
	e. 1 ges 2 no Other, specify: PLTSU36
f	Documented viral infection PLTIN 3×1
•	1 Uyes 54. Virus involved: PLT OV 31
	a. 1 Dyes 2 D no Cytomegalovirus (CMV) PLTOV 32.
	b. 1 \Box yes 2 \Box no Human Herpesvirus Type 6 (HHV6) $\mathcal{V} \subseteq T D V^{3/3}$
	c. 1 □ yes 2 □ no Herpes Simplex Virus (HSV) P-TDV34
	d. 1 🛛 yes 2 🗋 no Varicella PLT DU 35 e. 1 🖓 yes 2 🗋 no Other, specify:
g	Antimicrobial therapy PLTAM3X4
	1 Dyes 55. Therapy: PLTAM31
•	a. 1 yes 2 no Ganciclovir PLTAM32
	b. 1 ges 2 no Bactrim, Septra, Trimethoprim/Sulfamethoxazole PLTAM33
	c. 1 Dives 2 Dino Other specify: <u>PLTAM3CI</u>
h.	Veno-occlusive disease (VOD)
	20 no PLTVOD3
i	Undetermined
1.	
	20 no PLTUND3

Recipient - Recipient VMDP ID: - Last Name:
Er opoiesis 56
58. Did (does) recipient have evidence of hemolysis? HEMOLYS3
1 🗆 yes 59. Specify criteria:
Current Hematologic Findings
60. Date of most recent CBC:
Actual CBC values:
61. WBC: NO'L ACTUBC 3
62. Neutrophils: . % ALT NEU3
63 'mphocytes: 6 % ACTUM3
64. moglobin: g/dL ALTHGB3
65. Hematocrit: ACTACT3
66. Platelets:
67. Were chimerism studies performed prior to date of contact? CHIMSTD3
1 yes Complete table on following page
2 D no Continue with 68

cipient Recipient Last Name:					
cuto Graft vs. Host Disease (GVHD)					
 6 is specific therapy used post transplant to prevent acute GVHD or promote engraftment? PICAC. 3X11 1 yes 69. For each agent listed below indicate whether or not it was used to prevent acute GVHD or promote engraftment: PRAG31 a. 1 2 b. 1 2 Cyclosporine PRAG33 c. 1 2 Corticosteroids PRAG34 d. 1 2 Azathioprine PRAG36 f. 1 2 Cyclophosphamide PRAG37 g. 1 2 In vivo anti T-lymphocyte monoclonal antibody, specify: PRAG38 i. 1 i.					
0 Did acute GVHD occur? AGVHDYN3					
1 □ yes 71. Maximun overall grade: 1 □ 1 2 □ 11 3 □ 111 4 □ IV A 6 V H D M 6 3					
 72. Karnofsky/Lansky score at time of maximum severity of acute GVHD: (Refer to page 15 for complete scale) A 6 VHD KL3 73. What was the diagnosis based on? 1 □ Histologic evidence 2 □ Clinical evidence 3 □ Both 					
73. What was the diagnosis based on? I is Histologic evidence 2 is clinical evidence 3 is both 74. Date of onset:					
75. Is acute GVHD still present at time of this report?					
10 Yes AGUHDPR3					
2 D No 3 D Progressed to chronic GVHD					
4 D Not known					

List the maximum severity of organ involvement attributed to acute GVHD:

76. Skin AGUSKIN3

- 1 🛛 Stage 0 No rash
- 2 Stage 1 Maculopapular rash, < 25% of body surface
- 3 🗆 Stage 2 Maculopapular rash, 25-50% of body surface
- 4 🗆 Stage 3 Generalized erythroderma
- 5 🖸 Stage 4 Generalized erythroderma with bulbous formation and desquamation
- 77. Intestinal tract (use ml/day for adult recipients and ml/m²/day for pediatric recipients) AGUINTER
 - 1 🗆 Stage 0 No diarrhea
 - 2 □ Stage 0 Diarrhea ≤ 500 ml/day or < 280 ml/m²/day
 - 3 □ Stage 1 Diarrhea > 500 but ≤ 1000 ml/day or 280-555 ml/m²/day
 - 4 □ Stage 2 Diahrrea > 1000 but ≤ 1500 ml/day or 556-833 ml/m²/day
 - 5 🖸 Stage 3 Diarrhea > 1500 ml/day or > 833 ml/m²/day
 - 6 🗆 Stage 4 Severe abdominal pain, with or without ileus
- 78. Liver AGVLIVES
 - 1 □ Stage 0 Bilirubin < 2.0 mg/dL (< 34 µmol/L)
 - 2 🗆 Stage 1 Bilirubin 2.0-3.0 mg/dL (34-51 µmol/L)
 - 1 Stage 2 Bilirubin 3.1-6.0 mg/dL (51.1-102 µmol/L)
 - Stage 3 Bilirubin 6.1-15.0 mg/dL (102.1-255 µmol/L)
 - 5 LJ Stage 4 Bilirubin > 15.0 mg/dL (> 255 µmol/L)
 - 6 D Not evaluable, other liver process present

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Recipient		Name:				
7° ner organ involvemer) yes	1? AGOTH3¥Y a. 1□yes 2□no Up b. 1□yes 2□no Lur c. 1□yes 2□no Ott	A		13-1		
80. Was specific therapy us	ed to treat acute GVHD?	RA63×17)			
1 🗆 yes 2 🗔 no	b. 1 2 3 Cyd c. 1 2 3 Syd d. 1 2 3 Top e. 1 2 3 ALS f. 1 2 3 ALS f. 1 2 3 Cyd f. 1 2 3 Cyd h. 1 2 3 Cyd i. 1 2 3 That j. 1 2 3 In N j. 1 2 3 In N k. 1 2 3 Blir	w indicate whether indicate if dose was in thotrexate TRAG3 closporine TRAG3 stemic corticosteroids is, ALG, ATS, ATG T athioprine TRAG3 clophosphamide TRAG3 vivo anti T-lymphocy vivo immunotoxin, sp aded randomized tria er, specify:	increased): 2 33 ISTRAG3 TRAG35 TRAG36 S7 RAG38 S9 te monoclor becify: <u>JA</u> al, specify ag	TRAG3 	, specify: Zk	

Chronic Graft vs. Host Disease

82. Has recipient developed	d clinical chronic GVHD? CGUHDYN3
) yes	83. Øate of onset: Month Day Year CGVHDDT3
¥	84, Karnofsky/Lansky score at diagnosis of chronic GVHD: (Refer to page 15 for complete scale)
Continue with 95	85/Platelet count at diagnosis of chronic GVHD:
	86. Total serum bilirubin at diagnosis of chronic GVHD:
	87. What was the diagnosis based on?
	1 □ Histologic evidence 2 □ Clinical evidence CGVHDEV3 3 □ Both
	 88. Maximum grade of chronic GVHD: CGUHDMGB ✓ 1 □ Limited (Localized skin involvement and/or hepatic dysfunction due to chronic GVHD) 2 □ Extensive (Generalized skin involvement or localized skin involvement and/or hepatic dysfunction due to chronic GVHD, plus; – Liver histology showing chronic aggressive hepatitis, bridging necrosis or cirrhosis; or, – Involvement of eye: Schirmer's test with < 5 mm wetting; or – Involvement of minor salivary glands or oral mucosa demonstrated on labial biopsy; or – Involvement of any other target organ

and the second

Recipient NMDP ID:		Recipient Last Name:						<u> i</u>	: :
	89. Indicate if there v	CGV H? vas organ involve	ment with ch	ronic GVt	ID from lis	t belo	₩:		
)	b. 1 🛛 yes 2 🗖	no Cutaneous no Xerophthain no Oral involve no Mucositis, s	nia (dry eyes)C GJH H 33	32				
	e. 1 🗆 yes 2 🗆 f. 1 🗋 yes 2 🗔 g. 1 🗆 yes 2 🗔 h. 1 🗋 yes 2 🗔	no Esophogeal no Chronic nau no Chronic dial no Other GI tra	involvement isea/vomiting thea CG08 ct involveme	126043 126043 1437 112601	5				
	i. 1 🗋 yes 2 🗍 j. 1 🗋 yes 2 🗍 k. 1 🗋 yes 2 🗍 J. 1 🗋 yes 2 🗍 m. 1 🗋 yes 2 💭	no Hepatitis/he no Arthritis/arth no Contracture	CGVH3 patic involve ralgia (joint p SCGVH3 lung disease	mentCG pain)CG 12	0 +311				
	n. 1 🗆 yes 2 💭 o. 1 🗆 yes 2 💭 p. 1 🗋 yes 2 💭	no Serositis, sp no Myositis/my	ecify site: ≦ algia (tenden openia ∠60	<u>2GVH3</u> ness/pain 0H316	1-1	;) CC	504315		
	90. Was specific ther				2063	<u>×1</u>	Э		
	1 🗋 yes ——— 🔤 2 🗌 no	1. For each agen chronic GVHD		v indicate	١	es .	Dose increased.	Yes. no longei	r
)		a. ALS, ALG, ATS b. Azathioprine T c. Cyclosporine 1	RCG 33 TRCG34	l	1		2	saking 3	*□ •□ •□
		 d. Systemic cortico e. Topical cortico f. Cyclophosphai g. Thalidomide T 	steroids TR mide TRCG	CG36	1 1		2 🗆 2 🗆 2 🗆 2 🗆	3 D 3 D 3 D 3 D	
		h. In vivo anti T-ly antibody, spec	ity: TRCG				2 🗖	3 🗆	40
			RCG310				2 🗆	3 🗆	40
			TRCG31				2 🗆	30	40
	9	k. Other, specify: 2. Is the recipient				D nic G\	2 🗆 /HD? T(30 2064	40 N3
		1 U yes 2 U no	ſ	final treatr	ment was a				
	2 110	still present? SVHDPR s. recipient still rec		nent					

Recipient -	Last Name:
95 vere transfusions give	Clinical Status Post-Transplant In at any time after the start of conditioning to present? TRANSYN3
1 🗍 yes> 2 🗍 no	96. Did recipient receive only CMV seronegative blood products? 1 □ yes 2 □ no CMVNEGB 97. Were blood products filtered to reduce leukocytes?
98 Did recipient receivé af	1 Diges BPFILT3 2 Dino BPFILT3 by of the following agents for infection prophylaxis after start of conditioning to present? INPR3XL
1 yes 2 no	99. Specify: INPR3! a. 1 yes 2 no Polyclonal IV gamma globulin (not ATG) INPR32 b. 1 yes 2 no IV amphotericin INPR33 c. 1 yes 2 no Fluconazole INPR34 d. 1 yes 2 no Itraconazole INPR35 e. 1 yes 2 no Itraconazole INPR35 e. 1 yes 2 no Other systemic antifungal agent, specify: INPR36 f. 1 yes 2 no Other systemic antifungal agent, specify: INPR36 f. 1 yes 2 no Ganciclovir INPR37 g. 1 yes 2 no Ganciclovir INPR37 g. 1 yes 2 no Ganciclovir INPR38 h. 1 yes 2 no Ganciclovir INPR39 i. 1 yes 2 no Other antiviral agent, specify: INPR310 j. 1 yes 2 no Other antiviral agent, specify: INPR310 j. 1 yes 2 no Other antiviral agent, specify: INPR310 k. 1 yes 2 no Pentamidine INPR312 l. 1 yes 2 no Other pneumocystis prophylaxis, specify: NIPR313 m. 1 yes 2 no Other, specify: INPR314

Organ Function

Pulmonary Function

100: Did recipient develop interstitial pneumonitis after the start of conditioning to present? (Interstitial pneumonitis is characterized by hypoxia and diffuse interstitial infiltrates on chest x-ray not caused by fluid overload.)

1 🗆 yes	101. What was the date of onset?
	102. Were diagnostic tests done? PNTEST3 Year
Continue with 107	1 □ yes → 103. Diagnosis was evaluated by: PND1A3XJ a. 1 □ yes 2 □ no Bronchoalveolar lavage PNDIA31 b. 1 □ yes 2 □ no Transbronchial biopsy PNDIA32 c. 1 □ yes 2 □ no Open lung biopsy PNDIA33 d. 1 □ yes 2 □ no Autopsy PNDIA34
	e. 1 \Box yes 2 \Box no Other, specify: <u>PNDTA35</u>
	104. Was an organism isolated? $PN013 \times 3$ 1 \Box yes \longrightarrow 105. Etiology: $PN0131$ 2 \Box no \Box and \Box has a Province or init PMS 132.
	2 Ino a. 1 Jyes 2 no Pneumocystis carinii PNG 132 (idiopathic) b. 1 Jyes 2 no Aspergillus PNO 133 c. 1 Jyes 2 no Cytomegalovirus PNO 131
	d. 1 Dyes 2 D no Herpes simplex PNO 135 e. 1 Dyes 2 D no Adenovirus PNO 136 PNO 132
1	f. 1 🛛 yes 2 🗇 no Human Herpesvirus Type 6 (HHV6) g. 1 🖓 yes 2 🗇 no Other virus, specify: <u>PNo 138</u>
2.	h. 1 🛛 yes 2 🗆 no Other, specify: <u>PNO 139</u>
	106. Has interstitial pneumonitis resolved? 1 yes 2 no PNRESLV3

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Recipient .	Last Name:
12 ^r the recipient develo	p any of the following clinical signs/symptoms of abnormal liver function after the start of conditioning to
ent?	ALF3X6
a. 1 🗆 yes 2 🗆 no 🛛	
b. 1 🛛 yes 2 🗆 no 🕴	tepatomegaly ALF 32
	Right upper quadrant pain ALF 33
	Neight gain (> 5%) ALF 35
f. 1 🗆 yes 2 🗆 no (Dther, specify: ALF 36
	ver toxicity after the start of conditioning to present? LTYNS
1 🛛 yes	127. Date of onset:
2 🗖 no	
	128. Etiology: LTETICLS
	1 Veno-occlusive disease (VOD)
	2 Other, specify:
	3 🗆 VOD and other, specify:
	4 Unknown
	129. Diagnosis was based on: LTDIA 3 X5
	a. 1 yes 2 no Clinical signs and symptoms LTDIA31 b. 1 yes 2 no Elevated liver enzymes LTDIA32
	c. 1 yes 2 no Biopsy LTDIA33
	d 1 ves 2 no Autopsy $LTD \pm A^{34}$
	e. 1 Uyes 2 0 no Other, specify: LTDIA35
	130. Has liver toxicity resolved? LT RESLUB
	1 🗆 yes
	2 🗖 no
Kidney Function	
131. Recipient's serum creat	inine on day of contact: mg/dL SERCREA3
New Malignancy	
132 Did a new malignancy	lymphoproliferative or myeloproliferative disorder appear? NMYN3
1 🛛 yes	
2 🗆 no	133. Diagnosis: NMDIA3X4
	a. 1 U yes 2 0 no AML/MDS NMDIA31
	b. 1 U yes 2 D no B-cell lymphoproliferative disorder NMDIA32
	c. 1 🗆 yes 2 🗆 no Other lymphoma, specify: <u>NMDIA33</u>
	d. 1 🗆 yes 2 🗆 no Skin cancer, specify: <u>NMDTA34</u> e. 1 🗆 yes 2 🗆 no Solid tumor, specify: <u>NMDTA35</u>
	f. 1 yes 2 no Other, specify, including site: <u>NMPIA36</u>
	134. Date of diagnosis: Day Year NMDT3
Survival and Function	nal Status
_	ed from hospital after transplant? DISCHYN3
1 🛛 yes>	136. Date of first discharge from hospital after transplant:
2 🗖 no	DISCHDT3 Month Day Year
	137. Total number of inpatient days in first 100 days post-transplant:

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Recipient Recipient Last Name:	
13 ⁷ is the recipient alive on the day of contact? ALIVE J yes 2 □ no 139. If the recipient was alive on the c years or older and the Lansky So hospitalized for therapy according	ale for recipients younger than 16. Rate activity of recipients g to how they were functioning before hospitalization.
 KARNOFSKY SCALE ≥ 16 yrs ALNE Check the phrase in the Karnofsky Scale which best describes the activity status of the recipient: Able to carry on normal activity; no special care is needed □100 Normal; no complaints; no evidence of disease □90 Able to carry on normal activity □80 Normal activity with effort Unable to work; able to live at home, cares for most personal needs; a varying amount of assistance is needed 100 Cares for self; unable to carry on normal activity or to do active work 00 Requires occasional assistance but is able to care for most needs 00 Requires considerable assistance and frequent medical care Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly 10 Disabled; requires special care and assistance 10 Severely disabled; hospitalization indicated, although death not imminent 10 Moribund; fatal process progressing rapidly 	 LANSKY SCALE < 16 yrs Select the phrase in the Lansky Play-Performance Scale which best describes the activity status of the recipient: Able to carry on normal activity; no special care is needed 1000 Fully active 90 Minor restriction in physically strenuous play 80 Restricted in strenuous play, tires more easily, otherwise active Mild to moderate restriction 70 Both greater restrictions of, and less time spent in. active play 60 Ambulatory up to 50% of time, limited active play with assistance/supervision 50 Considerable assistance required for any active play; fully able to engage in quiet play Moderate to severe restriction 40 Able to initiate quiet activities 30 Needs considerable assistance for quiet activity 20 Limited to very passive activity initiated by others (e.g., TV)

Disease Status and Treatment Post-Transplant

Questions 140–166 are disease specific questions. For this section, only answer the questions that pertain to the disease that was reported for this recipient on the Form 120, 520, 620.

Leukemia, Lymphoma, MDS, Other Malignancy (If recipient's original diagnosis was CML only answer questions 146-163.)

140. What is (was) the status of recipient's disease at time of this report or at time of death? LLSTAT3

 First complete remission post transplant (no hematologic evidence of disease) 	Continue with 167
2 Therapy-induced complete remission after	141. Date of first relapse: Month Day Year
persistent disease	142. Site of relapse: $L R S 3 X Y$
or relapse post	a. 1 U yes 2 U no Blood and/or bone marrow LLRS31
· · · · · · · · · · · · · · · · · · ·	b. 1. Dyes 2 D no CNS LL RS33
Relapse or persistent	c. 1 Dyes 2 D no Testes LLR SB3
disease	d. 1 🛛 yes 2 🗖 no Other, specify: LLRS34

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CML Only

146. Did Chronic Myelogenous Leukemia recur (include clinical and/or cytogenetic relapse) post-transplant? CMRECHN3



Recipient NMDP ID:		Recipient Last Name:
	157. Was recipient 1 □ yes → 2 □ no	treated for post-transplant relapse? CMTRYN3 158. What treatments were given? CMTRT3X a. 1 yes 2 no Interferon gamma CMTRT31 b. 1 yes 2 no Interferon alpha CMTRT32 c. 1 yes 2 no Chemotherapy CMTRT33 d. 1 yes 2 no Chemotherapy CMTRT33 d. 1 yes 2 no Mithdrawal of immunosuppression CMTRT34 e. 1 yes 2 no Immunotoxins CMTRT35 f. 1 yes 2 no Donor leukocytes CMTRT36 g. 1 yes 2 no Second transplant CMTRT37 h. 1 yes 2 no Growth factors, specify: CMTRT37 h. 1 yes 2 no Other, specify: CMTRT37 i. 1 yes 2 no Other, specify: CMTRT37 159. Did recipient achieve hematologic remission? CMHEMPERS 1 yes 2 no 3 not applicable 160. Did recipient achieve cytogenetic remission? CMLRYN3 1 yes 2 no 3 not applicable 161. Date bone marrow examined: CMCRD7 Month Day Year 162. Did recipient achieve chronic phase? 1 yes CMCRCP3 2 no 3 not applicable, cytogenetic relapse only Continue with 163
		Cont. with 163

163. At the time of this report, CML was (check one box only): CMLSTAT 3

- 1 🛛 Absent
- 2 Present on cytogenetic testing only
- 3 🛛 In chronic phase
- 4 In accelerated phase
- 5 🔲 in blast phase

Continue with 167

Aplastic Anemia, Nonmalignant Hematologic Disorders, Inborn Errors of Metabolism

164. What was the status of original disease at the time of this report? NHDSTATS

- 1 🛛 Cured
- 2 D Improved
- 3 Unchanged
- 5 🛛 Unknown

Continue with 167

Recipient _ Last Name:									<u> </u>
mr odeficiency Disease (For SCIDS complete Insert I; for)	WAS complete	e Insert l	I, and ai	nswe	r que	estions	165 a	and 16i	6.)
im. Odeficiency Disease (i bi colbe complete and			-< T r	91	3				
165iat was the status of T-cell function at this visit or at the time	of death?		<u> </u>						
1 D Absent (< 10% normal response)									
3 🔲 Partial 4 🔲 Unknown									
The set the visit or at the time	of death?	F De	SST	٩T	3				
166. What was the status of B-cell function at this visit or at the time		~~~~~~	<u> </u>		/				
1 □ Absent (≤ 10% normal response) 2 □ Normal									
3 🗆 Partial									
4 🔲 Unknown	1								
Subsequent Stem Cell Infusion Complete this section if recipient has received a subsequent stem ce	all infusion. If (the dono	r is a se	cond	unre	elated o	ionor.	compl	ete a
Complete this section if recipient has received a subsequent sterif content formation relative to the subsequent sterif content sterif	equent infusio	JN.						,	
167 Date of subsequent stem cell infusion:	Year	Sc	IDT	3					
168. What was the indication for subsequent stem cell infusion?	CIND	૧							
1 🔲 Graft failure/rejection									
2 C Recurrence of disease									
3 Other, specify:									
169 Tree of stem cells: SCISRCA3							•		
Autologous									
 Cryopreserved bone marrow Cryopreserved peripheral blood stem cells 									
2 Allogeneic, unrelated					•				
1 Eresh, original donor bone marrow									
2 Cryopreserved original donor bone marrow									
 3 E Fresh, second donor bone marrow 4 E Fresh, original donor mobilized peripheral blood stem 	cells								
5 Cryopreserved original donor mobilized peripheral blo	od stem cells								
6 Fresh, second donor <i>mobilized</i> peripheral blood stem	cells								
MDP cord blood ■ Non-NMDP cord blood									
3 🔲 Allogeneic, related									
1 🛛 Bone marrow									
2 Peripheral blood									
3 Cord blood									
170. Signed: Person comp									
Person comp	leting form								
Please print name:									
. ()									
E-mail address:									
NMDP Form 130, 530, 630 V8 (18–18) November 1998									

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National Marrow Donor Program® Six Month to Two Year	Unrelated	Recipient
Follow-Up Visit of Recipient	Recipient Last Name: Related	Unique Recipient Number (UPN):
Sequence Number:	Unrelated and Related Today's Date:	Recipient Local
Date Received:	Date of Trans	plant for which this form
		Marrow PBSC Cord blood (Form 140) (Form 540) (Form 640)
······································	amination by t	onor Marrow Transplant for CML Recipient
 Date of actual contact with recipient to determine Did recipient receive a subsequent stem cell in report? STEMCEL4 ▲ yes Answer questions ❑ no 	fusion (bone mar	Month Day Year Trow, mobilized peripheral blood stem cells, cord blood) since la
3. Did recipient die since last report? DIED4	•	

1 🛛 yes>	Answers to subsequent questions should reflect clinical status immediately prior to death.
2 🗆 no ————	Answers to subsequent questions should reflect clinical status on day of actual contact for this follow-up evaluation.

4. Has recipient received an infusion of peripheral blood mononuclear cells or lymphocytes from the donor since last report?

1 Uyes 2 ID no PBMCDR4	5. Date the first infusion was given: Month Day Year PBMC DT4
PBMCDAM	6. Recipient weight within 2 weeks of first infusion: kg PPMCWTH
	7. Total number of infusions:
	8. Total dose of mononuclear cells:
	 9. Indication for the infusion(s) of donor cells: 1 □ Relapse 2 □ Treatment for B cell lymphoproliferative disorder 3 □ Prophylaxis against B cell lymphoproliferative disorder 4 □ Graft failure 5 □ Viral infection, specify:

Recipient NMDP ID:	-	Recipient Last Name:	
	-		

atopoietic Reconstitution Post-Transplant

10. Has the recipient received hematopoietic, lymphoid growth factors or cytokines since last report? HLAFC4

1 🛛 yes ———	11. Specify agents given:		وينافلهم وبوروم ورون	ومؤوسه المحافظ المراجع المراجع المراجع المراجع	an a changal ang	XANGGERANG CONTRACTOR	ineres and			
2 🗖 no		Yes	No	- Month	Date started Day	l Yoar	Month	Date stopped Day	Year	Code (below)
									104	
GCSFAD B4/E4	a. G-CSF	1 🗆	2 🗖					<u>」</u>		
GMAD BUJEY BRYTAD BUJEY	b. GM-CSF	1 🗆	2 🗆		J L L L					
ERYTAD BULEY	c. Erythropoietin	1 🗆	2 🗖							
THROAD BY 152	d. Thrombopoietin	1 🗆	2 🗖							
ILZAD	e. Interleukin – 2 (IL-2)	٦ ٦	2 🗖							
ILSAD	f. Interleukin – 3 (IL-3)	1 🛛	2 🗖							
IL6AD	g. Interleukin – 6 (IL-6)	1 🗖	2 🗖							1
PIXYAD	h. PIXY - 321	1 🗆	2							
SCFAD	i. Stem Cell Factor	1 🗆	2 🗖							\square
ALPHAD	(SCF) j. Interferon alpha	1 🗆	2 🗖							\square
GAMMAD	k. Interferon gamma	1 🛛	2 🗆							\square
Barad	I. Blinded growth factor trial, specify agent:	1 🗖	2 🗖							
OTHRAD	m. Other, specify:	1 🛛	2 🗆						<u> </u>	\square
			-					·	میں استان کا انتخاب ک مراجع کا انتخاب کا ان	
INDC4X13	 Intervention for delay/de Intervention for delay/de Intervention for delay/de Intervention for delay/de 	ecline in ecline in	absolute platelets both AN	e neutrophil s IC and plate	lets	5	Antileukem Antileukem	nic or tumor agen nic or tumor agen vention therapy	t (prevent t (treatme	ion) nt)
	12. After being off growth f factors or cytokines po				days, did	the recipie	ent receiv	ve other cou	ses of	growth
	1 🗆 yes 2 🔲 no 3 💭 unknown		•	C304						

.

Recipient NMDP ID:		ecipient					
.ulopoiesis 13. Did the recipient achiev days) since last report? 1 □ Yes		• • • • • • • • • • • • • • • • • • •	0/mm ³ for 3 col		b values c	bbtained on diff	erent
	 14. Date ANC ≥ 500/mm³ (f 15. Was ANC ≥ 1,000/mm³ 	ANC	NDTY	Month	Day Day ab values?	Year Year	
	1 □ yes 2 □ noANCNUYN4 Continue with 16	Date (first c lab values):	of 3 consecutive	Month	Day	Year	

2 D No, recipient's initial hematopoietic recovery was recorded on a previous report

Continue	e with	16

3 □ No, recipient has never achieved an ANC ≥ 500/mm³ for three consecutive lab values obtained on different days and there is no evidence of recurrent disease

Continue with 26

4 □ No, recipient has never achieved an ANC ≥ 500/mm³ for three consecutive lab values obtained on different days and there was documented persistent malignant disease post-transplant

Continue with 68

16. Following initial hematopoietic recovery (ANC ≥ 500/mm³ for three consecutive lab values obtained on different days) did the recipient experience a subsequent decline in ANC to < 500/mm³ for greater than three days since last report?

□ yes 2 □ no ANCYVN4	17. Date of decline in ANC to < 500/mm ³ for greater than Image: Comparison of the second secon
∀	Actual CBC on first day of decline: ANCY DDT4
Continue with 31	18. WBC:
	19. Neutrophils: % ANC NEU 4
	20. Lymphocytes: % ANCLYMU
	21. Did recipient recover and maintain ANC ≥ 500/mm ³ following the decline?
	2 Ino 22. Date of ANC recovery:
	23. WBC: X 109/L ANC RWBCH
	24. Neutrophils: . % ANCRNEU4
	Continue with 26 25. Lymphocytes: % ANCRLYML

Recipient -	· · · · · · · · · · · · · · · · · · ·	Recipient Last Name:	
a. Persistent disease or relapse	failure to achieve ANC \geq 50 ANC PDR \downarrow	00/mm ³ or a decline in ANC:	
 b. Immune mediated rejection 2 □ no ANCIMUX c. Graft versus host disease 1 □ yes 2 □ no ANCGV 	d. 1 🗆 yes 2 🗆 no	Cellular Antibody Third party engraftment	
d. Non-viral infection 1 □ yes 2 □ no e. Suspected viral ∠infection	VT-4 28. Suspected virus:		
ANC SV 4X6	b. 1 🛛 yes 2 🗆 no		
Documented viral infection 1 uses 2 no ANC DV 4X6	b. 1 🛛 yes 2 🗆 no		
g. Antimicrobial therapy 1 ges 2 no h. Undetermined 1 ges 2 no h. Undetermined 1 ges 2 no	c. 1 □ yes 2 □ no V	Bactrim, Septra, Trimethoprim/Sulfamethoxazole	

Megakaryopoiesis

The following questions relate to *initial* platelet recovery. All dates should reflect no transfusions in previous 7 days, and the first of 3 consecutive laboratory values obtained on different days.

.

31. Did recipient ac	chieve an initial plate	let count of \geq 20,000	since last report?	PLIZLRY
----------------------	-------------------------	----------------------------	--------------------	---------

1 Yes Continue with 32	-
2 □ No, recipient achieved a platelet count of ≥ 20,000 prior to current report but < 50,000	Continue with 34
3 □ No, recipient achieved a platelet count of ≥ 50,000 prior to current report but < 100,000	Continue with 36
□ No, recipient achieved a platelet count of ≥ 100,000 prior to current report	Continue with 40
5 □ No, recipient never achieved a platelet count of ≥ 20,000	Continue with 49

NMDP ID:		Recipient Last Name:
Vas a	a platelet count o	$f \ge 20.000 \text{ achieved}? PLIQYN4$
	es>	33. Date platelets ≥ 20,000:
		Continue with 38
-		f ≥ 50,000 achieved? PLISYN4
1 🗆 y	es>	35. Date platelets ≥ 50,000: Month Day Year PLISDT4
		Continue with 38 f > 100,000 achieved? PLI 10 YN Y
36. Was a	a platelet count of	f ≥ 100,000 achieved? PLL 10 7 V 9
1 🗆 y 2 🗆 n	es >	37. Date platelets ≥ 100,000: Month Day Year PLI10 DT4
		telet transfusion independent? PLTTIYN4
_1 □ y	es>	39. Is the date of the last platelet transfusion known?
		1 □ yes PLITJ DTH 2 □ no PLITJ DTH PLITJKNH Month Day Year If recipient was platelet transfusion independent for ≥ 14 days and then subsequently experienced a decline in platelet count and required platelet transfusions, record date of last platelet transfusion before decline in counts. If recipient has not required platelet transfusions since initial platelet recovery, record date of last platelet transfusion.
2 🗆 n)	Continue with 51
\fter i	nitial recovery to	platelet count ≥ 20,000 did the platelet count decline to < 20,000 for 3 consecutive laboratory values or a
	e to < 20,000 for es	one laboratory value and the recipient received a platelet transfusion?
· · · · · · · · · · · · · · · · · · ·		
PL:	IDYN4	41. Date of the first day platelet count declined below 20,000:
PL.	IDYN4	42. Has platelet count recovered? Month Day Year 1 □ yes Continue with 43 PLTDDT4
	I DYN4 PLIRYA	42. Has platelet count recovered? Month Day Year 1 □ yes Continue with 43 PLIDDT4 2 □ no Continue with 49
2 🗆 ni	IDYN4 PLIRYA	42. Has platelet count recovered? Month Day Year 42. Day Continue with 43 PLIDDT4 2 no Continue with 49 Continue with 49 Continue with 49
2□n The followin	I DYN 4 PLIRYA D	42. Has platelet count recovered? Month Day Year 1 □ yes Continue with 43 PLIDDT4 2 □ no Continue with 49
2 □ no The followin should refle 43. Was a	I DYN 4 PLIRYA ng date questions ect no transfusion platelet count of	42. Has platelet count recovered? 42. Has platelet count recovered? 42. Has platelet count recovered? 42. Has platelet count recovered? 43. Month Day Year PLIDDT↓ Continue with 43 Continue with 49 5 relate to subsequent platelet recovery following a decline of platelet count to below 20,000. All dates
2 □ no The followin should refie 43. Was a 1 □ ye	L D Y N 4 PLIRYA pdate questions ect no transfusion platelet count of platelet count of	42. Has platelet count recovered? 42. Has platelet count recovered? 42. Has platelet count recovered? 42. Has platelet count recovered? 43. Month Day Year PLIDDT4 PLIDDT4 Continue with 49 5. relate to subsequent platelet recovery following a decline of platelet count to below 20,000. All dates as in previous 7 days, and the first of 3 consecutive laboratory values.
2 □ no The followin should refle 43. Was a 1 □ ye	L DYN 4 PLIRYA ong date questions ect no transfusion platelet count of es	42. Has platelet count recovered? Month Day Year 42. Has platelet count recovered? Month Day Year 44. Date platelets $\geq 20,000$: Continue with and the first of 3 consecutive laboratory values.
2 □ no The followin should refle 43. Was a 1 □ ye PLS 2 2 □ no 45. Was a	L DYN4 PLIRYA pdate questions pdate questions platelet count of platelet count of PVN4	42. Has platelet count recovered? Month Day Year 1 yes Continue with 43 $PLEDDT4$ 2 no Continue with 49 Continue with 43 Continue with 43 2 no Continue with 49 Continue with 49 Continue with 49 S relate to subsequent platelet recovery following a decline of platelet count to below 20,000. All dates as in previous 7 days, and the first of 3 consecutive laboratory values. $\geq 20,000$ achieved? $= 20,000$: $= 20,000$: $= 20,000$: 44. Date platelets $\geq 20,000$: $= 20,000$: $= 20,000$: $= 100, 000, 000, 000, 000, 000, 000, 000$
2 🗆 no The followin should refle 43. Was a 1 🗆 ye 2 🗆 no 45. Was a	L DYN4 PLIRYA PLIRYA ong date questions ict no transfusion platelet count of PLIRYA PLIRYA	42. Has platelet count recovered? Month Day Year 1 yes Continue with 43 $PLIDDT4$ 2 no Continue with 49 Continue with 49 Continue with 49 Continue with 49 S relate to subsequent platelet recovery following a decline of platelet count to below 20,000. All dates as in previous 7 days, and the first of 3 consecutive laboratory values. \geq 20,000 achieved? \downarrow $PLS2D74$ 44. Date platelets \geq 20,000: \square \square Month Day Year Continue with 49
2 □ no The followin should refle 43. Was a 1 □ ye 2 □ no 45. Was a 1 □ ye PLS	L DYN4 PLIRYA PLIRYA ong date questions ect no transfusion platelet count of Platelet count of platelet count of S 5 YN4	42. Has platelet count recovered? Month Day Year 1 yes Continue with 43 $PLEDDT4$ 2 no Continue with 49 Continue with 43 Continue with 43 2 no Continue with 49 Continue with 49 Continue with 49 S relate to subsequent platelet recovery following a decline of platelet count to below 20,000. All dates as in previous 7 days, and the first of 3 consecutive laboratory values. $\geq 20,000$ achieved? $= 20,000$: $= 20,000$: $= 20,000$: 44. Date platelets $\geq 20,000$: $= 20,000$: $= 20,000$: $= 100, 000, 000, 000, 000, 000, 000, 000$
2 □ no The followin should refie 43. Was a 1 □ ye 2 □ no 45. Was a 1 □ ye PLS 2 □ no	L DYN4 PLIRYA PLIRYA ong date questions ect no transfusion platelet count of platelet count of platelet count of S5 YN4	42. Has platelet count recovered? Month Day Year 1 yes Continue with 43 PLIDDT4 2 no Continue with 49 PLIDDT4 Continue with 49 S relate to subsequent platelet recovery following a decline of platelet count to below 20,000. All dates as in previous 7 days, and the first of 3 consecutive laboratory values. 20,000 achieved? 44. Date platelets \geq 20,000: PLS2D74 Continue with 49 250,000 achieved? PLS5D74 46. Date platelets \geq 50,000: Month Day Year Month Day Year PLS5D74 Continue with 49
2 □ no The followin should refte 43. Was a 1 □ ye 2 □ no 45. Was a 1 □ ye 2 □ no 47. Was a □ ye 2 □ no	L DYN4 PLIRYA PLIRYA ong date questions ect no transfusion platelet count of platelet count of 55 YN4 platelet count of s	42. Has platelet count recovered? Month Day Year 1 \bigcirc yes \bigcirc Continue with 43 $PLIDDT4$ 2 no \bigcirc Continue with 49 Second platelet count with 49 Continue with 49 Second platelet recovery following a decline of platelet count to below 20,000. All dates are in previous 7 days, and the first of 3 consecutive laboratory values. \geq 20,000 achieved? \square

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Recipient	Recipient Last Name:
 recipient now receiving platelet transfusion 1 yes — Continue with 51 	ns?
PLSRECH 1 yes 2 no 3 previous PLS/ <nw< th=""><th>Note last platelet transfusion known? Month Day Year Note PLS DT4 Note PLS DT4 Not</th></nw<>	Note last platelet transfusion known? Month Day Year Note PLS DT4 Note PLS DT4 Not
 51. Suspected etiology of failure to achieve a plata. a. Persistent disease or relapse 1 □ yes PLTPDR4 2 □ no 	atelet count ≥ 100,000 or decline in platelet count to < 20,000:
	☐ no Cellular ☐ no Antibody ☐ no Third party engraftment
Non-viral infection 1 yes 2 no PLTNVI4	
2 no b. 1 yes 2	Ino Cytomegalovirus (CMV) Ino Human Herpesvirus Type 6 (HHV6) Ino Herpes Simplex Virus (HSV) Ino Varicella
f. Documented viral infection 1 □ yes 2 □ no P(TDV4X6 f. Virus involved: a. 1 □ yes 2 □ b. 1 □ yes 2 □ c. 1 □ yes 2 □ d. 1 □ yes 2 □ e. 1 □ yes 2 □ e. 1 □ yes 2 □	I no Herpes Simplex Virus (HSV) I no Varicella
g. Antimicrobial therapy 1 □ yes 2 □ no PCTAM4×4 h. Veno-occlusive disease (VOD)	I no Ganciclovir I no Bactrim, Septra, Trimethoprim/Sulfamethoxazole I no Other, specify:
1 □ yes 2 □ no PLT VO D4 i. Undetermined 1 □ yes 2 □ no PLTUND4	

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Recipient Recipient Last Nam	
nropoiesis 56. Has recipient received red blood cell (RBC) transfusions with 1 yes 2 no RBCRECH 57. Is the date of the last RBC transfusions 1 yes 2 no RBCRECH Continue with 58	
 58. Did (does) recipient have evidence of hemolysis? 1 □ yes 2 □ no 59. Specify criteria: (e.g., fragmented red cells, sph HEMOUS 4 	erocytes, hemoglobinuria, etc.)
60. Date of most recent CBC:	
Actual CBC results:	ar and a second se
61. WBC: • × 10%/L M TWBC 62. Neutrophils: • % ACTNEUL	
Lymphocytes: • % ACTLYA 64. Hemoglobin: • g/dL □ not tested	ACTHGB4
65. Hematocrit: • % □ not tested 66. Platelets: • × 10 ⁹ /L	ACTPLT4
67. Were chimerism studies performed prior to date of contact?	
2 no ——— Continue with 68	

.

Recipi NMDP		-]-[]]	Recipient Last Name:			
	Percent Unknown Origin (Third Party) Cells 'Non- Ouant. Quant.							
of contact.)	Percent Host Cetts 'Non- Quant. Quant.							andicate cell type) 5 - Red cells 6 - Monocytes 7 - Neutrophils 8 - Other, specify:
imerism studies performed prior to date of contact.)	Percent Donor Cells Non- Quant. Quant.							Valid Cell Types Valid Cell Types (Insert number in box above to indicate cell type) w (BM) 5 - Red cells v (BM) 5 - Red cells lood mononuclear cells (PBMC) 6 - Monocytes 7 - Neutrophils 8 - Other, spec
m studies perfor	Number of Unknown Origin (Third Party) Cells						ty cells by (+).	Valid Ceil Type (Insert number in box above to Bone marrow (BM) - Peripheral blood mononuclear cells (PBMC) - T-cells - B-ceils
	Number of Host Cells						of donor, host, or third-party cells by (+).	1 - Bone m 2 - Periphe 3 - T-cells 4 - B-cells
ner information	Number of Donor Cells						The of donor, hi) reaction (PCR)
n Studies (Provide date(s), method(s) and other information for	Number of Cells Examined Total Cells						If performed by non-quantitative method, indicate the presence	Valid Method CodesValid Method Codes(Insert number in box above to indicate method used)cytogenetics4 - Polymerase chain reaction (PCR)nt in situ hybridization (FISH)5 - HLA serotypingn fragment-length6 - VNTRnisms (RFLP)7 - Other, specify:
date(;	Cell Type (See valid list below)							ethod ove to iSH)
ovide	Method (See valid list below)							alid M box at ation (F
n Studies (Pr	Date N Day Year V						med by non-quantite	Valid Methoc (Insert number in box above t 1 - Standard cytogenetics 2 - Fluorescent in situ hybridization (FISH) 3 - Restriction fragment-length polymorphisms (RFLP)
Chim	Month						* If perfor	1 - Stani 2 - Fluor 3 - Restr
NMDP F	Form 140, 540 ht © 1998 Nat	, 640 V5 (8–1 ional Marrow	8) Novem Donor Prog	ber 1998 gram. All righ	ts reserved.			

t vs. Host Disease (GVHD)

68. (For six month report only) Was acute GVHD present at time of 100-day post-transplant report?

1 🛛 yes	69. Is acute GVHD still present at time of this report?
3 🗆 not known	1 Dyes 2 Dno AGVHDNOW
AGVHD100	3 D progressed to chronic GVHD 4 D not known

70. Did acute GVHD occur for the first time (or a flare-up that was more severe) after the 100-day post-transplant report or since

1 ges	71. Maximun overall grade: 1 0 1 2 0 11 3 0 11 4 0 1V
2 □ no ACVHDYNY 3 □ not known	72. Karnofsky/Lansky score at time of maximum severity of acute GVHD: (Refer to page 15 for complete scale)
Continue with 82	73. What was the diagnosis based on? 1 I Histologic evidence 2 I Clinical evidence 3 I Both
	74. Date of onset:
	Month Day Year A G V H D 7 4 75. Is acute GVHD still present at time of this report?
	1 DYes 2 DNO AGVHDPRY
	2 D No AGVAUTA 3 D Progressed to chronic GVHD
	4 🗆 Not known
	List the maximum severity of organ involvement attributed to acute GVHD:
	76. Skin AVGSKINY
	1 □ Stage 0 – No rash / V V V V V V V V V V V V V V V V V V
	3 🛛 Stage 2 – Maculopapular rash, 25-50% of body surface
	4 Stage 3 – Generalized erythroderma 5 Stage 4 – Generalized erythroderma with bulbous formation and desgamation
	77.9Intestinal tract (use ml/day for adult recipients and ml/m²/day for pediatric recipients)
	1 □ Stage 0 – No diarrhea 2 □ Stage 0 – Diarrhea ≤ 500 ml/day or < 280 ml/m²/day
	3 □ Stage 1 – Diarrhea > 500 but ≤ 1000 ml/day or 280-555 ml/m²/day
	4 □ Stage 2 – Diahrrea > 1000 but ≤ 1500 ml/day or 556-833 ml/m²/day 5 □ Stage 3 – Diarrhea > 1500 ml/day or > 833 ml/m²/day
	8 □ Stage 4 – Severe abdominal pain, with or without ileus
	78. Liver AVGLIVEL
	1 Stage 0 – Bilirubin < 2.0 mg/dL (< 34 µmol/L) 2 Stage 1 – Bilirubin 2.0-3.0 mg/dL (34-51 µmol/L)
	3 🗖 Stage 2 - Bilirubin 3.1-6.0 mg/dL (51.1-102 µmol/L)
	4
	6 D Not evaluable, other liver process present
	79. Other organ involvement? 1 □ yes> a 1 □ yes 2 □ no 1 inner Gi tract
	AGOTH 4X4 c. 1 🛛 yes 2 🗆 no Other, specify:

Recipient NMDP ID:	-	-		ecipie ast Na			
		80. Was specific the	erapy u	sed to	treat	acute C	SVHD?
		1 🗆 yes ———————————————————————————————————					below indicate whether or not it was used to treat vas already receiving agent, indicate if dose was
		TRAGUX13		crease yes		increase	
			1	10		3 🔲	Methotrexate
		and the second				3 🔲	
		194					Systemic corticosteroids
		r^{2} , $\mu_{e,eeb}$					Topical corticosteroids
							ALS, ALG, ATS, ATG
		The start of the				з 🗖	Azathioprine
		a Barra da Carta da C					Cyclophosphamide
		Constant of				3 🗖	Thalidomide
		t de la constance de la constan La constance de la constance de	i.	1 🗖	2 🗖	3 🗖	In vivo anti T-lymphocyte monoclonal
							antibody, specify:
			j.	1 🗖	2 🗖	3 🗖	In vivo immunotoxin,
•			k.	1 🗆	2 🗖	3 🗖	specify:Blinded randomized trial,

82. Did recipient have chronic GVHD at time of last report?

□ yes>	Continue with 89 CAVHDLR4
83. Has recipient developed	clinical chronic GVHD since last report?
1 I yes	84. Date of onset:
	85. Karnofsky/Lansky score at diagnosis of chronic GVHD: (Refer to page 15 for complete scale)
Continue with 96	86. Platelet count at diagnosis of chronic GVHD:
	87. Total serum bilirubin at diagnosis of chronic GVHD; Unit of measurement: 1
	88. What was the diagnosis based on?
	1 □ Histologic evidence 2 □ Clinical evidence CGVHDBUH 3 □ Both

Other agents, specify: _____

- 89. Maximum grade of chronic GVHD: CGVH DEVH
 - 1 Limited (Localized skin involvement and/or hepatic dysfunction due to chronic GVHD)
 - 2 Extensive (Generalized skin involvement or localized skin involvement and/or hepatic dysfunction due to chronic GVHD, plus;
 - Liver histology showing chronic aggressive hepatitis, bridging necrosis or cirrhosis; or,
 - Involvement of eye: Schirmer's test with < 5 mm wetting; or
 - Involvement of minor salivary glands or oral mucosa demonstrated on labial biopsy; or
 - Involvement of any other target organ

Recipient NMDP ID:	-	Recipient Last Name:							

idicate if there was organ involvement with chronic GVHD from list below:

		0.0	
a.	1 🛛 yes	2 🗖 no	Cutaneous involvement CGVH41 MULT
b.	1 🛛 yes	2 🗖 no	Xerophthalmia (dry eyes) 742 000000000
C.	1 🛛 yes	2 🗖 no	Oral involvement 43
d.	1 🛛 yes	2 🗖 no	Mucositis, specify site:
e.	1 🛛 yes	2 🗋 no	Esophogeal involvement 45
f.	1 🛛 yes	2 🗖 no	Chronic nausea/vomiting 46
g.	1 🛛 yes	2 🗖 no	Chronic diarrhea 47
h.	1 🛛 yes	2 🗖 no	Other GI tract involvement
i.	1 🛛 yes	2 🗖 no	Weight loss
j.	1 🛛 yes	2 🗖 no	Hepatitis/hepatic involvement $\dot{u}iO$
k.	1 🛛 yes	2 🗖 no	Arthritis/arthralgia (joint pain) 4///
1.	1 🛛 yes	2 🗖 no	Contractures 4/2
m.	1 🛛 yes	2 🗖 no	Obstructive lung disease 4/3
n.	1 🛛 yes	2 🗖 no	Serositis, specify site:
О.	1 🛛 yes	2 🗖 no	Myositis/myalgia (tenderness/pain in muscles) 415
			Thrombocytopenia 446
q.	1 🛛 yes	2 🗖 no	Other, specify: VH17

91. Was specific therapy used to treat chronic GVHD?

1 🛛 yes	92. For each agent listed below indicate whether or not it was	used to tr	eat chronic	: GVHD:	
2 🗖 no	& TREGYXTZ	Yes, still taking	Dose increased, still taking	Yes, no longer taking	No
	a. ALS, ALG, ATS, ATG	1 🗖	2	3 🗖	4 🗆
	b. Azathioprine	1 🖸	2 🗖	3 🗖	4 🗆
	c. Cyclosporine	1 🖸	2 🗖	3 🗖	4 🗆
	d. Systemic conticosteroids TRGC44	1 🖸	2 🗖	3 🗖	4 🗆
	e. Topical corticosteroids TRGCUS	1 🗖	2 🗖	3 🗖	4 🗆
	T. Cyclophosphamide	1 🔟	2 🗖	3 🗖	40
	g. maidonide	10	2 🗖	3 🗖	4 🗆
	h. In vivo anti T-lymphocyte monoclonal antibody, specify:	1 🛄	2 🗖	3 🗖	40
	i. In vivo immunotoxin, specify:	10	2 🗖	3 🛛	40
	j. Blinded randomized trial, specify agent:	1 🗖	2 🗖	3 🗖	40
	k. Other, specify:	1 🖸	2 🗖	3 🗖	40
	93. Is the recipient still receiving treatment for chronic GVHD?	TRC	egyn	+	
	2 □ no 94. Date final treatment administered: TRCGDTH	Month	Day	Year	
Ĺ					

95. Is chronic GVHD still present?

1 🛛 yes

2 🗖 no

CGV HDPR4

3 I no symptoms, recipient still receiving treatment

Recipient - - Recipient IMDP ID: - - Last Name:

r Function Post-Transplant

Pulmonary Function

96. Has recipient developed interstitial pneumonitis since last report? (Interstitial pneumonitis is characterized by hypoxia and diffuse interstitial infiltrates on chest x-ray not caused by fluid overload.)



103. Did recipient develop pulmonary abnormalities other than interstitial pneumonitis since the last report?





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Recipient -	Recipient Last Name:
Did recipient develop lin 1 🛛 yes	ver toxicity since the last report? 124. Date of onset:
	126. Diagnosis was based on: Image: Additional signs and symptoms Image: Additional signs and symptoms a. 1 in yes 2 in on Clinical signs and symptoms Image: Additional signs and symptoms b. 1 in yes 2 in on Elevated liver enzymes Image: Additional signs and symptoms c. 1 in yes 2 in on Biopsy Image: Additional signs and symptoms Image: Additional signs and symptoms d. 1 in yes 2 in on Autopsy Image: Additional signs and symptoms Image: Additional signs and symptoms e. 1 in yes 2 in on Other, specify: Image: Additional signs and symptoms Image: Additional signs and symptoms
	127. Has liver toxicity resolved? 1 ves 2 no UTRSLV4
Kidney Function	

128. Recipient's most recent se	rum creat	inine:		mg/dL	SERCHEAU
129. Date of serum creatinine:				St	SECR DTY
	Month	Day	Year		

r Organ Impairmant/Disorder

130. Since the last reported contact has the recipient developed any other clinically significant organ impairment or disorder?

	-		
1 🗆 yes	131. From the list below,	indicate what organ impairment/dis	sorder occurred:
2 L ho	a. 1 🛛 yes 2 🗆 no	Renal failure requiring dialysis	DOR4
TDYNY	b. 1 🗆 yes 2 🗆 no	TTP/HUS or similar syndrome	TYZER
	c. 1 🗆 yes 2 🗔 no	Hemorrhage, specify site:	43
	d. 1 🗆 yes 2 🗔 no	Seizures	44
	e. 1 🗆 yes 2 🗋 no		45
	f. 1 🗆 yes 2 🗆 no		46
	g. 1 🗆 yes 2 🗋 no	Gonadal dysfunction	47
		Growth disturbance/growth horm	one deficiency 48
	i. 1 🗆 yes 2 🗖 no	Hemorraghic cystitis	. 49
	j. 1 🗆 yes 2 🗋 no	Other, specify:	410

New Malignancy

132. Did a new malignancy, lymphoproliferative or myeloproliferative disorder appear since the last report?

1 Dyes 2 Dno NMYNY	C. 1 ☐ yes 2 ☐ no d. 1 ☐ yes 2 ☐ no e. 1 ☐ yes 2 ☐ no	AML/MDS B-cell lymphoproliferative disorder Other lymphoma, specify:	NMDFA4) 42 43 44 44 44 46		
	134. Date of diagnosis:	Month Day Year	NMD74		

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Recipient - Recipient NMDP ID: - Last Name:	
2 🗆 no 16 years or older and the Lansky	on date of contact, check "no.") lay of contact, complete the Karnofsky Scale for recipients Scale for recipients younger than 16. Rate activity of recipients g to how they were functioning before hospitalization.
ALTNEKLY KARNOFSKY SCALE ≥ 16 yrs Check the phrase in the Karnofsky Scale which best describes the activity status of the recipient: Able to carry on normal activity; no special care is needed 1 100 Normal; no complaints; no evidence of disease 2 90 Able to carry on normal activity 3 80 Normal activity with effort Unable to work; able to live at home, cares for most personal needs; a varying amount of assistance is needed 4 70 Cares for self; unable to carry on normal activity or to do active work 5 60 Requires occasional assistance but is able to care for most needs 6 50 Requires considerable assistance and frequent medical care Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly 7 40 Disabled; requires special care and assistance 8 30 Severely disabled; hospitalization indicated, although death not imminent 9 20 Very sick; hospitalization necessary 10 10 Moribund; fatal process progressing rapidly	LANSKY SCALE < 16 yrs

Disease Status and Treatment Post-Transplant

Questions 137–163 are disease specific questions. For this section, only answer the questions that pertain to the disease that was reported for this recipient on the Form 120, 520, 620.

Leukemia, Lymphoma, MDS, Other Malignancy (If recipient's original diagnosis was CML only answer questions 143-160.)

137. What is (was) the status of recipient's disease at time of this report or at time of death?

1 🗆	First complete remission post transplant (no hematologic evidence of disease)	Continue with 164
2 🗖	Therapy-induced complete remission after persistent disease	138. Date of first relapse:
	or relapse post transplant	a. 1 up yes 2 up no Blood and/or bone marrow
- D	Relapse or	b. 1 🗆 yes 2 🗆 no CNS 42 c. 1 🗆 yes 2 🗆 no Testes 43
	persistent disease	d. 1 🛛 yes 2 🗆 no Other, specify:

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Recipient	·	-	Recipient Last Name:							
		140. Was recipient t 1 🗇 yes ——— 2 🗍 no	141. What treatm a. 1 ges b. 1 ges c. 1 ges d. 1 ges d. 1 ges e. 1 ges f. 1 ges f. 1 ges g. 1 ges h. 1 ges i. 1 ges	ents wer 2 □ no 2 □ no	e given? Interfero Interfero Chemoti Withdraw Immuno Donor le Second Growth	n alpha herapy wal of imi toxins ukocytes transplar factors, s	munosu i it pecify: .	ppres	0	
		142. Did the recipier 1 yes 2 no 3 not applica	ble LLH	iologic re EM化					 	

CML Only

143. Did Chronic Myelogenous Leukemia recur (include clinical and/or cytogenetic relapse) post-transplant?

	144. Was post-trans	plant relapse extramedullary o	only? CMEMDTY
CMRECYM	1 🛛 yes —> 2 🗋 no	plant relapse extramedullary o 145. Date of extramedullary n	elapse:
	CMEMYNY	146. Site of relapse, specify: .	Month Day Year
Continue with 160		Continue with 154	
		transplant relapse cytogenetic	c only?
	1 🗆 yes —— 2 🗆 no	148. Date of cytogenetic relap	
	CMCYYNN	CMBNDTH 149 Did bematologic evidence	Month Day Year e of CML subsequently appear?
		1 ges	e of hematologic relapse:
		CMHEY NY CMHE	
		<u> </u>	Month Day Year
		Cont. with 154 151. Initia	al hematologic relapse findings were consistent
		1 🗆	Chronic phase
			Accelerated phase
			nue with 154
×			
		-transplant relapse hematolog	ic findings consistent with:
	1 Chronic ph 2 Chronic Accelerated	or blast phase - 153. Date	e of relapse: CMPTDT4
	CMPTCO		
			Month Day Year

Recipient NMDP ID:	-	Recipient Last Name:							
·		eated for post-tran 155. What treatme a. 1 yes b. 1 yes c. 1 yes d. 1 yes d. 1 yes e. 1 yes f. 1 yes f. 1 yes f. 1 yes f. 1 yes i. 1 yes 2 no 3 not applie 2 no 3 not applie extramed relapse of 4 not tested CMCRYN + Cont. with 160	ents were 2 □ no 2 □	e given? Interferon g Interferon a Chemother Withdrawal Immunotox Donor leuk Second trai Growth fact Other, spec hematologic CM i cytogenetic 158. Date t	Alpha apy of immu ins ocytes nsplant tors, spe- ify: remissio pone mai month cipient a ot applica	cify: on? m? Day chieve 1 C R able; cy	chronic	: CMC Year phase?	

160. At the time of this report, CML was (check one box only):

- 1 🛛 Absent
- 2 D Present on cytogenetic testing only
- 3 🛛 In chronic phase
- 4 🗖 In accelerated phase
- 5 🛛 In blast phase

Continue with 164

Aplastic Anemia, Nonmalignant Hematologic Disorders, Inborn Errors of Metabolism

CML STAT4

161. What was the status of original disease at the time of this report?

- 1 🛛 Cured
- 2 Improved
- 3 Unchanged
- 4 Worse
- 5 🗖 Unknown

Continue with 164

NHDSTATH

Recipient	-	Recipient Last Name:	

I' inodeficiency Disease (For SCIDS complete Insert I; for WAS complete Insert II, and answer questions 162 and 163.)

162. What was the status of T-cell function at this visit or at the time of death?

- 1 □ Absent (< 10% normal response)
- 2 🛛 Normal
- 3 D Partial
- 4 🛛 Unknown

TOSTATY

163. What was the status of B-cell function at this visit or at the time of death?

- 1 □ Absent (≤ 10% normal response)
- 2 D Normal 3 D Partial

IDBSTAT 4

4 🛛 Unknown

Subsequent Stem Cell Infusion

Complete this section if recipient has received a subsequent stem cell infusion. If the donor is a second unrelated donor, complete a new Form 120, 520, 620 for baseline information relative to the subsequent infusion.

164	. Date of subsequent stem cell infusion:
165	What was the indication for subsequent stem cell infusion?
	1 Graft failure/rejection 2 Recurrence of disease 3 D Other, specify:
17	ource of stem cells: I autologous SCIGRCAH 1 autologues Cryopreserved bone marrow 2 Cryopreserved peripheral blood stem cells SCISRCBH 1 Fresh, original donor bone marrow SCISRCBH 2 Cryopreserved original donor bone marrow SCISRCBH 3 Fresh, second donor bone marrow SCISRCBH 4 Fresh, original donor mobilized peripheral blood stem cells SCISRCBH 5 Cryopreserved original donor mobilized peripheral blood stem cells SCISRCBH 6 Fresh, second donor mobilized peripheral blood stem cells SCISRCBH 7 NMDP cord blood Stem cells 8 Allogeneic, related NMDP cord blood 9 Allogeneic, related Scient cells 9 Cord blood Scient cells
167.	Signed:
	Person completing form Please print name:
	Phone: ()
	rāx: ()
	E-mail address:

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Hational Marrow Donor Program® Yearly Follow-Up for Greater Than Iwo Years Post-Transplant Registry Use Only Sequence Number Date Received Survival Status 1 Is the recipient alive? 1 Use 2. Give date of most	P(C)
Continue with Continue with Complete For Complete For Continue with Answers to subser	h: m 190 and Month Day Year decth d+
Functional Status N5 Kay omplete the Kamofsky Scale for recipeints 16 vate activity of recipients hospitalized for therap	py according to how they were functioning before hospitalization.
KARNOFSKY SCALE > 16 yrs	LANSKY SCALE < 16 yrs
Check the phrase in the Karnofsky Scale white	
oescribes the activity status of the recipient:	which best describes the activity status of the recipient:
Able to carry on normal activity; no specia needed	al care is Able to carry on normal activity; no special care is needed
1 100 Normal; no complaints; no evidence 2 90 Able to carry on normal activity 3 80 Normal activity with effort Unable to work; able to live at home, cares	e of disease 1
personal needs; a varying amount of assis	
needed	4 70 Both greater restrictions of, and less time spent in,
4 70 Cares for self; unable to carry on ni or to do active work	ormal activity active play 5
5 5 60 Requires occasional assistance but	
care for most needs 6	and frequent 6 50 Considerable assistance required for any active play; fully able to engage in quiet play
medical care	Moderate to severe restriction
Unable to care for self; requires equivalent	t of 7
institutional or hospital care; disease may	
progressing rapidly 7 7 40 Disabled: requires special care and	9 20 Limited to very passive activity initiated by others (e.g., TV)
8 30 Severely disabled; hospitalization in	
although death not imminent	
 9 20 Very sick: hospitalization necessary 10 10 Moribund: fatal process progressing 	
NMOP Form 150, 550, 650 V2 (1-4) November 1998	Mail this form to: The NMDP Registry, Suite 500, 3433 Broadway St. N.E. Minneapolis, MN 55413 Retain a copy at the transplant center.

NMDP ID		- <u> </u>	Recipient Last Name:			
5 Did tř 1 🗆 y 2 🗆 n	io	ve chronic GVHD at the tir Continue with qui velop chronic GVHD since	estion 8	Chrn	oguhd	•
۲ŪŶ		7. Date of onset: Continue wit		Aonth Day	Year	egund ndt
	ite the maximum imited (Localize xtensive (Gene Liver histology	Continue with que m grade of GVHD since th skin involvement and/or h ralized skin involvement or snowing chronic aggress f eye. Schirmer's test with	ne last report: Gut nepatic dysfunction du localized skin involve sive hepatitis, bridgin	ment and/or hep	atic dysfunction due to	
-	involvement o	f eye. Schirmer's test with f minor salivary glands or f any other target organ		strated on labial	biopsy: or	

9 Is chronic GVHD still present at the time of this report? guhdpres

1 🗆 yes

2 🗆 no

New Malignancies

Did a new malignancy, lymphoproliferative or myeloproliferative disorder appear?

• 🖸 yes	11. Diagnosis:	
	a. 1 🗆 yes 2 🗆 no	AMLMOS MMdias!
nmyn5		B-cell lymphoproliferative disorder 1 m and 3 a
•		Other lymphoma, specify:
	d. 1 🗆 yes 2 🗆 no	Skin cancer, specify: <u>0 m d a S 9</u>
		Solid tumor, specify: <u>nm dla 55</u>
	f. 1 🗆 yes 2 🗆 no	Other, specify, including site: <u>nmdla56</u>
	12. Date of diagnosis:	Month Day Year nmd+5

Other Organ Impairmant/Disorder

13 Since the last reported contact has the recipient developed any other clinically significant organ impairment or disorder?

1 🛛 yes	14. From the list below, indicate what organ impairment/disorder occurred:					
2 🗆 no	. [™] a. 1 🗆 yes 2 🗆 no	Renal failure requiring dialysis or renal				
orimpair		TTP/HUS or similar syndrome orttphus				
•••	c. 1 🗆 yes 2 🗆 no	Hemorrhage, specify site: or he main				
	d. 1 🗆 yes 2 🗆 no	Seizures orseizur				
1	e. 1 🛛 yes 🛛 2 🗌 no	Cataracts or cutar				
	f. 1 🗋 yes 2 🗋 no	Hypothyroidism Unhypoth				
	g. 1 🗆 yes 2 🗆 no	Gonadal dysfunction ongonad Growth disturbance/growth hormone deficiency ongrowth				
	h. 1 🗋 yes 2 🗖 no	Growth disturbance/growth hormone deficiency on growth				
1	i. 1 🗆 yes 2 🗆 no	Hemorraghic cystilis or CY8+1+				
	j. 1 🗆 yes 2 🗆 no	Other, specify: On other				

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						•	
) se Status Post-Transp) niy answer the section that corres 15. Acute and Chronic Leukemias, L 1	ponds with the diagno	nancies	orm 120. Ltch	520, 63	20.		
2 Chemotherapy induced remission after persistent disease or relapse Mo	e of first relapse for this t Day Day arst relapse date for this	Year	-		ed		

- 17 Aplastic Anemia, Nonmalignant Hernatologic Disorders, Inborn Errors of Metabolism
 - 1 Cured
 - 2 D Improved
 - 3 D Unchanged
 - ₄ □ Worse
 - 5 Unknown

nodeficiency Disease m

18 what was the status of T-cell function at this visit or at the time of death?

aplsanem

- □ Absent (≤ 10% normal response)
 - : D Normal

trelstat

3 🖸 Partial

4 🖸 Unknown

19 What was the status of B-cell function at this visit or at the time of death?

- · □ Absent (≤ 10% normal response)
- : I Normal
- : 🗆 Partial
- ± □ Unknown

pcelstat

Month

sclind 5

Subsequent Stem Cell Infusion

emplete this section if patient has received a subsequent stem cell infusion. If the donor was a second unrelated donor, complete new Form 120, 520, 620 for baseline information relative to the subsequent infusion.

22 Date of subsequent stem cell infusion:

Dav	Y



21 What was the indication for the subsequent stem cell infusion?

- : Graft/failure rejection
- :
 Recurrent disease
 - Cther. specify

	Cipient - Recipient Last Name		1		į .		
2	nurce of stem cells SCISICQS Autologous 1 Cryopreserved bone marrow 2 Cryopreserved peripheral blood stem cells				•		
	 2 Allogeneic, unrelated 1 Fresh, original donor bone marrow 2 Cryopreserved original donor bone marrow 3 Fresh, second donor bone marrow 4 Fresh, original donor mobilized peripheral blood stem 5 Cryopreserved original donor mobilized peripheral blood stem 6 Fresh, second donor mobilized peripheral blood stem 7 NMDP cord blood 7 Non-NMDP cord blood 	ood stem celi	5	Type	-scisr	cb5	
	 Allogeneic, related Bone marrow Peripheral blood Cord blood 			•			
23	Signed				,		
	Person comp	ieung torm					
	Please print name:						
	.ione number: ())						

Fax number (_____

E-mail address

)