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Form 8: Post Transplant Annual Followup

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Not Started

- 1 Was patient seen for follow-up this year**
- Yes, patient was seen this year
 - No, patient was not seen this year or the patient follow-up falls outside the follow-up window (+/- 90 days of the transplant anniversary)
 - No, patient transferred care to another center (not at time of annual follow-up)

PTYSR

1b Last Date of Followup at Your Center

Question Added: 01 JAN 1996
LDFDATE

2 Date of Follow-Up

This is the date the patient was seen and the date for which the data on the form is current.
It is not the date that the form is filled out.

Question Added: 01 JAN 1996
SRDATE

8a

3 Current residence ZIP code/Postal Code

9 digit zip code preferred if available but not required.

Missing Reason:
 Unknown

Question Added: 01 JAN 1996
RES_ZIP

Height and Weight

4 Height

- Centimeters
- Inches

Question Added: 01 JAN 1996

_SRHTU

Missing Reason:
 Not Done
 Unknown

_SRHT

Calculated

BSA: n/a
BMI: n/a

5 Weight

- Kilograms
- Pounds

Question Added: 01 JAN 1996

_SRWTU

Missing Reason:
 Not Done
 Unknown

_SRWT

6 Were Hemodynamics Performed? Yes
 No
 Unknown

If yes, enter the most representative hemodynamics.

Question Added: 01 JAN 1996
F8HEMO

6a Hemodynamics
 If done during annual surveillance biopsy (if performed)
 or during coronary assessment.
 MM/DD/YYYY

Missing Reason:
 Unknown

Question Added: 01 JAN 1996
F8DOHEM

6b AoM
 Aortic Mean mmHg

Range Information
 Too Low: < 0
 Normal: Between 0 and 150
 Question Zone: > 151
 Red Flag Zone: > 151

Missing Reason:
 Not Done
 Unknown

Question Added: 01 JAN 1996

F8AOM

6c RAm (RAP or CVP)
 Right Atrial Mean Pressure mmHg

Range Information
 Too Low: < 0
 Normal: Between 0 and 40
 Question Zone: > 41
 Red Flag Zone: > 41

Missing Reason:
 Not Done
 Unknown

Question Added: 01 JAN 1996

F8RAM

6d PAm
 Pulmonary Arterial Mean mmHg

Range Information
 Too Low: < 0
 Normal: Between 0 and 50
 Question Zone: > 51
 Red Flag Zone: > 51

Missing Reason:
 Not Done
 Unknown

Question Added: 01 JAN 1996

F8PAM

6e PCW LV EDP
 Pulmonary Capillary Wedge mmHg

Range Information
 Too Low: < 0
 Normal: Between 0 and 60
 Question Zone: > 61
 Red Flag Zone: > 61

Missing Reason:
 Not Done
 Unknown

Question Added: 01 JAN 1996

F8PCW

6f C.O.
 Cardiac Output L/min

Range Information
 Too Low: < 0
 Normal: Between 0 and 20
 Question Zone: > 21
 Red Flag Zone: > 21

Missing Reason:
 Not Done
 Unknown

Question Added: 01 JAN 1996

F8CO

6g C.I.
 Cardiac Index L/min/m²

Range Information
 Too Low: < 0
 Normal: Between 0 and 15
 Question Zone: > 16
 Red Flag Zone: > 16

Missing Reason:
 Not Done
 Unknown

Question Added: 01 JAN 1996

F8CI

7 Is patient currently followed at your PHTS Transplant center? Patient currently followed at our PHTS Transplant center
 Patient followed exclusively at another center

Question Added: 01 JAN 1996
FOLATCEN

7a If currently followed All care is provided at our center
 Only yearly evaluation at our center

Question Added: 01 JAN 1996
F8CARE

7a.i If only followed yearly, specify date PHTS event followup ceased

Missing Reason:
 Unknown

Question Added: 01 JAN 1996
YEDATE

1b Last Date of Followup at Your Center

Question Added: 01 JAN 1996
LDFDATE

Medications

Which medications to include:

- Immunosuppressants
- Cardiovascular medications (diuretics, antihypertensives, antiarrhythmics)
- Infection prophylaxis
- All other daily medications
- Chronic meds that are intermittent (e.g. weekly meds)
- We are no longer categorizing medications by indication of use as intent is very difficult to assess and some medications may be used for multiple indications and have multiple effects despite intended use for only one indication or another

Which medications NOT to include:

- PRN
- Topical/otic/ophthalmic meds
- Over the counter supplements (multivitamins, etc.)
- Short term courses of medications (e.g. 7 days of amoxicillin for acute otitis media)
- Oxygen

Medications

Question Added: 01 JAN 1996

Cardiovascular

- Aldosterone Antagonist (Spironolactone) med_AldosteroneAntagonist
- Alpha adrenergic blockers (ex: doxazosin, prazosin, terazosin) med_Alphaadrenergicblockers
- Alpha Blocker med_AlphaBlocker
- Amiodarone med_Amiodarone
- Angiotensin II receptor blocker (ARBs) (ex: Azilsartan (Edarbi), Candesartan (Atacand), Eprosartan, Irbesartan (Avapro), Losartan (Cozaar), Olmesartan (Benicar), Telmisartan (Micardis), Valsartan (Diovan) med_ARB
- Angiotensin-Converting-Enzyme (ACE) inhibitors (ex: captopril, enalapril, lisinopril, ramipril etc) med_ACE
- Beta Blockers (ex: atenolol, metoprolol, nadolol etc.) med_BetaBlockers
- Calcium Channel blockers (ex: Amlodipine (Norvasc), Diltiazem (Cardizem, Tiazac, others), Felodipine, Isradipine, Nicardipine, Nifedipine (Adalat CC, Afeditab CR, Procardia), Nisoldipine (Sular) med_CalciumChannelblockers
- Carvedilol med_Carvedilol
- Clonidine med_Clonidine
- Digoxin med_Digoxin
- Diuretics (loops, thiazides, etc.) med_Diuretics
- Dobutamine med_Dobutamine
- Endothelial Receptor Antagonist med_EndothelialReceptorAntag
- Entresto med_Entresto
- Milrinone med_Milrinone
- Nitrates (nitroglycerin, etc.) med_Nitrates
- PDE-5 inhibitors (sildenafil, etc.) med_PDE5inhibitors
- PGE med_PGE
- Vasodilators (hydralazine) med_Vasodilators
- Vasopressin antagonist (tolvaptan, conivaptan, etc.) med_Vasopressin
- Other antiarrhythmic, specify med_Otherantiarrhythmic
- Other cardiovascular medication, specify med_Othercardiovasc

Other antiarrhythmic, specify

med_Otherantiarrhythmic_osp

Other cardiovascular medication, specify

med_Othercardiovascsp

Anti-Hyperlipidemics

- Fish oil/Omega-3/Lovaza med_Omega3
- Statin med_Statin
- Other cholesterol medication, specify med_Othercholesterol

Other cholesterol medication, specify

med_Othercholesterol_osp

Anticoagulants

- Aspirin med_Aspirin
- Clopidogrel med_Clopidogrel
- Dipyridamole med_Dipyridamole
- Enoxaparin med_Enoxaparin
- Warfarin med_Warfarin
- Other anticoagulant, specify med_Otheranticoagulant

Other anticoagulant, specify

med_Otheranticoagulant_osp

Anti-Infectives

- Acyclovir/valacyclovir med_Acyclovir
- Amphotericin B med_AmphotericinB
- Azoles (fluconazole, voriconazole, Itraconazoles ,
posaconazole, ketaconazole etc) med_Azoles
- Bactrim (Sulfamethoxazole/Trimethoprim) med_Bactrim
- Dapsone med_Dapsone
- Echinocandins (casofungin, micafungin,
anidulafungin) med_Echinocandins
- Ganciclovir/valganciclovir med_GanciclovirValganciclovir
- HIV Antiviral med_HIVAntiviral
- Nystatin med_Nystatin
- Pentamidine med_Pentamidine
- Other Antifungal, specify med_OtherAntifungal
- Other Antiviral, specify med_OtherAntiviral
- Other chronic antibiotic, specify med_Otherchronicantibiotic

Other Antifungal, specify

med_OtherAntifungal_osp

Other Antiviral, specify

med_OtherAntiviral_osp

Other chronic antibiotic, specify

med_Otherchronicantibiotic_osp

Endocrine

- Anti-osteoporosis (bisphosphonate, etc.) med_Antiosteoporosis
- Growth Hormone med_GrowthHormone
- Insulin med_Insulin
- Oral anti-hyperglycemic med_Oralanthyperglycemic
- Oral contraceptive/patch contraceptive/Norplant med_Contraceptive
- Thyroid hormone (synthroid) med_Thyroidhormone
- Other endocrine, specify med_End_Oth

Other endocrine, specify

med_End_Othsp

GI

- H2 blocker med_H2blocker
- PPI med_PPI
- Other antacid, specify med_Otherantacid

Other antacid, specify

med_Otherantacid_osp

Neuro/Psych

- Anti-anxiety med_Antianxiety
- Antidepressant med_Antidepressant
- Antipsychotic med_Antipsychotic
- Mood stabilizer med_Moodstabilizer
- Narcotic (chronic use, not prn) med_Narcotic_chronic
- Non-stimulant ADHD med_NonstimulantADHD
- NSAID (chronic use, not prn) med_NSAID_chronic
- Stimulant ADHD med_StimulantADHD
- Other neuro-psych, specify med_Otherneuropsych

Other neuro-psych, specify

med_Otherneuropsych_osp

Pulmonary

- Inhaled Beta-agonist med_InhaledBetaagonist
- Inhaled Steroid med_InhaledSteroid
- Oral Leukotriene inhibitor med_OralLeukotrieneinhibitor
- Other inhaled bronchodilator, specify med_Otherinhaledbronchodilator
- Other oral asthma medication, specify med_Otheroralasthmamed

Other inhaled bronchodilator, specify

med_Otherinhaledbronch_osp

Other oral asthma medication, specify

med_Otheroralasthmamed_osp

Supplements

- Albumin infusion med_Albumininfusion
- Carnitine med_Carnitine
- CoQ med_CoQ
- Pancreatic Enzymes med_PancreaticEnzymes
- Probiotic med_Probiotic
- Other supplement, specify med_Othersupplement

Other supplement, specify

med_Othersupplement_osp

Immunosuppressants

- Anakinra med_Anakinra
- Azathioprine med_Azathioprine
- Basiliximab med_Basiliximab
- Cyclophosphamide med_Cyclophosphamide
- Cyclosporine med_Cyclosporine
- Everolimus med_Everolimus
- Immune Globulin med_ImmuneGlobulin
- Methotrexate med_Methotrexate
- MMF med_MMF
- Rituximab med_Rituximab
- Sirolimus med_Sirolimus
- Steroids med_Steroids
- Tacrolimus med_Tacrolimus
- Other immunosuppressant, specify med_imm_oth

Other immunosuppressant, specify

med_imm_othsp

Bone Marrow Stimulant

- Avatrombopag med_Avatrombopag
- Erythropoietin stimulating agents (ex: procrit, epogen, Darbepoetin) med_Erythropoietinstimulating
- granulocyte colony-stimulating factor (G-CSF) (ex: filgrastim, pegfilgrastim) med_GCSF
- granulocyte-macrophage colony-stimulating factor (GM-CSF) (ex: Sargramostim- SAP) med_GMCSF
- Lusutrombopag med_Lusutrombopag
- Thrombopoetic growth factor (ex: Eltrombopag, Romilpostim) med_Thrombopoetic
- Other bone marrow stimulant, specify med_Bonemarrowsup

Other bone marrow stimulant, specify

med_Bonemarrowsupsp

Other

- Allopurinol med_Allopurinol
- Other, specify med_Other

med_Other_osp

8b Did the patient receive treatment at any time since the last follow-up for hypertension? Yes No Unknown

Check for medications used to treat hypertension

Question Added: 29 JUL 2019
Follow_hyperten

8b.i Specify medication class:

- Alpha adrenergic blockers (ex: doxazosin, prazosin, terazosin) Hyperten_AAB
- Angiotensin-Converting-Enzyme (ACE) inhibitors (ex: captopril, enalapril, lisinopril, ramipril etc) Hyperten_ACE
- Angiotensin II receptor blocker (ARBs) (ex: Azilsartan (Edarbi), Candesartan (Atacand), Eprosartan, Irbesartan (Avapro), Losartan (Cozaar), Olmesartan (Benicar), Telmisartan (Micardis), Valsartan (Diovan) Hyperten_ARBS
- Beta Blockers (ex: atenolol, metoprolol, nadolol etc) Hyperten_Beta
- Calcium Channel blockers (ex: Amlodipine (Norvasc), Diltiazem (Cardizem, Tiazac, others), Felodipine, Isradipine, Nifedipine, Nifedipine (Adalat CC, Afeditab CR, Procardia), Nisoldipine (Sular) Hyperten_CCB
- Clonidine Hyperten_Clonidine
- Diuretics (loops, thiazides) Hyperten_diuretics
- Vasodilators (hydralazine) Hyperten_vaso
- Other, specify Hyperten_other

Hyperten_other_osp

Question Added: 29 JUL 2019

8b.ii Is the patient still currently on medication for hypertension? Yes No Unknown

Question Added: 29 JUL 2019
Hyperten_now

8c Have there been any signs of non-adherence in the last year?

Check all that apply

- Patient/caregiver missed >1 appointment this year (ask annually)?
- Patient acknowledged missing doses (more than just a rare occasion)

- Patient often had drug levels outside of the target ranges without a biological explanation
- Patient failed to pick up prescription(s)?
- No signs of non-adherence NonCompliance
- Other, specify

Question Added: 22 JUN 2023

9

Schooling

- Completed high school, >18 yo CHSCHLFU
- Delayed grade level DLSCHLFU
- Not applicable, <6 years NASCHLFU
- Special education SESCHLFU
- Status unknown UKSCHLFU
- Within one grade level AASCHLFU

Question Added: 01 JAN 1996

10

Exercise Test

- Yes
- No
- Unknown

Question Added: 01 JAN 1996
F8EXPERF

10a

If exercise test not performed, specify reason

- Age inappropriate
- Too sick
- Not Routinely Done
- Unknown
- Other, specify

F8TTNDRS

F8TTNDR

10b

Max VO₂% Predicted for Age

Refers to predicted maximum VO₂ for patient (should be listed in exercise report; if not, exercise lab personnel should be able to provide this data)

%

Missing Reason:

- Not Done
- Unknown

Question Added: 01 JAN 2010

F8VO2AGE

10c

VO₂ at follow-up

Maximum oxygen consumption ml/kg/min

Missing Reason:

- Not Done
- Unknown

F8MVO2

10d

Respiratory Value at Peak

RER or Respiratory Quotient:R Value at peak is the respiratory quotient of carbon dioxide production divided by oxygen consumption, and is used as an index of how vigorously the patient exercised.

A value above 1.05 is generally considered to represent an adequate effort.

Missing Reason:

- Not Done
- Unknown

Question Added: 07 OCT 2015

F8RVALU

11

Primary insurance at followup

- Charitable Donation
- Free
- Government
- Private
- Self Pay

PRIINS

- Unknown
- Other, specify

INSPOTH

Question Added: 01 JAN 1996

- **Charitable Donation** – Indicates that a company, institution or individual(s) donated funds to pay for the care of the listed patient.
- **Free** – Indicates that the listing hospital will not charge the patient for the cost of the hospitalization
- **Government** – Other US or state government insurance. For Example, Medicaid, Medicare, CHIP (Children’s Health Insurance Program), Department of VA refers to funds from the Veterans Administration or others. Includes Single Payer Non-US.
- **Private** – Refers to funds from agencies such as Blue Cross/Blue Shield, etc. This also includes TRICARE.
- **Self Pay** – Indicates that the recipient will pay for the largest portion of the cost of the hospitalization.
- **Other** – For example, funds from a foreign government. Specify foreign country in the space provided.

Laboratory Values closest to time of this report

Note: labs may have been collected on different dates.

12a	Total Bilirubin	<input style="width: 90%;" type="text"/> <input type="radio"/> mg/dL <input type="radio"/> umol/L	Range Information Too Low: < 0 Normal: Between 0.3 and 1.2 Question Zone: > 2.4 Red Flag Zone: > 10	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
		BILITF_U	BILITF		
12b	Direct Bilirubin	<input style="width: 90%;" type="text"/> <input type="radio"/> mg/dL <input type="radio"/> umol/L	Range Information Too Low: < 0 Normal: Between 0 and 0.2 Question Zone: > 0.4 Red Flag Zone: > 5	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
		BILIDF_U	BILIDF		
12c	AST <small>Aspartate transaminase (also SGOT)</small>	<input style="width: 90%;" type="text"/> U/L	Range Information Too Low: < 0 Normal: Between 10 and 60 Question Zone: > 120 Red Flag Zone: > 1000	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
		ASTF	ASTF		
12d	ALT <small>Alanine transaminase (also SGPT)</small>	<input style="width: 90%;" type="text"/> U/L	Range Information Too Low: < 0 Normal: Between 7 and 45 Question Zone: > 90 Red Flag Zone: > 1000	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
		ALTU	ALTU		
12e	BNP <small>B-type natriuretic peptide</small>	<input style="width: 90%;" type="text"/> pg/mL or ng/L	Range Information Too Low: < 0 Normal: Between 10 and 100 Question Zone: > 1000 Red Flag Zone: > 10000	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 2010
		BNPF	BNPF		
12f	Pro BNP <small>Pro NT B-type natriuretic peptide</small>	<input style="width: 90%;" type="text"/> <input type="radio"/> pg/mL or ng/L <input type="radio"/> pmol/L	Range Information Too Low: < 0 Normal: Between 10 and 300 Question Zone: > 3000 Red Flag Zone: > 30000	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 07 OCT 2015
		PROBNPF_U	PROBNPF		
12g	HbA1c	<input style="width: 90%;" type="text"/> Percentage	Range Information Too Low: < 3 Normal: Between 3 and 6 Question Zone: > 9 Red Flag Zone: > 14	Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done	Question Added: 22 JUN 2023
		HbA1c	HbA1c		

12h	Creatinine	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> umol/L	Range Information Too Low: < 0 Normal: Between 0.2 and 1.3 Question Zone: > 2.6 Red Flag Zone: > 10	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1996	
		CREATF_U				
CREATF						
12i	BUN	Blood urea nitrogen	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> Urea mmol/L	Range Information Too Low: < 0 Normal: Between 4 and 20 Question Zone: > 40 Red Flag Zone: > 120	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1996
		BUNF_U				
BUNF						
12j	Cystatin C	mg/L	Range Information Too Low: < 0 Normal: Between 0.5 and 1.4 Question Zone: > 2.8 Red Flag Zone: > 10	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 07 OCT 2015	
		CSTATF				
CSTATF						
12k	Total Protein	<input type="text"/> <input type="radio"/> g/dL <input type="radio"/> g/L	Range Information Too Low: < 0 Normal: Between 3.6 and 8.1 Question Zone: > 12 Red Flag Zone: > 16	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1999	
		TPFU_U				
TPFU						
12l	Serum Albumin	<input type="text"/> <input type="radio"/> g/dL <input type="radio"/> g/L	Range Information Too Low: < 0 Normal: Between 1.9 and 5.8 Question Zone: > 10 Red Flag Zone: > 12	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1999	
		SAFU_U				
SAFU						
12m	Cholesterol	Total Cholesterol	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	Range Information Too Low: < 50 Normal: Between 50 and 199 Question Zone: > 300 Red Flag Zone: > 600	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1996
		CHOLF_U				
CHOLF						
12n	TG	Triglycerides	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	Range Information Too Low: < 0 Normal: Between 28 and 149 Question Zone: > 250 Red Flag Zone: > 500	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1996
		TGF_U				
TGF						
12o	LDL	Low density lipoprotein	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	Range Information Too Low: < 40 Normal: Between 40 and 159 Question Zone: > 250 Red Flag Zone: > 500	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1996
		LDLF_U				
LDLF						
12p	HDL	High density lipoprotein	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	Range Information Too Low: < 10 Normal: Between 35 and 55 Question Zone: > 70 Red Flag Zone: > 80	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1996
		HDLF_U				
HDLF						
12q	VLDL	Very low density lipoprotein	<input type="text"/> <input type="radio"/> mg/dL <input type="radio"/> mmol/L	Range Information Too Low: < 0 Normal: Between 2 and 30 Question Zone: > 60 Red Flag Zone: > 250	Missing Reason: <input type="radio"/> Not Done <input type="radio"/> Unknown	Question Added: 01 JAN 1996
		VLDLF_U				
VLDLF						
12r	Hemoglobin	(gm/dL)	<input type="text"/>	Range Information Too Low: < 6 Normal: Between 8 and 15 Question Zone: > 16 Red Flag Zone: > 20	Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done	Question Added: 22 JUN 2023
		HEMATO_U				
HEMATO						
	Hematocrit		<input type="text"/>	Range Information Too Low: < 18 Normal: Between 24 and 45	Missing Reason:	Question Added: 22 JUN 2023
		HEMATO_U				
HEMATO						

12s

Percentage

Question Zone: > 46
Red Flag Zone: > 60

Unknown
 Not Done

12t

WBC

10^3 per cmm

Range Information
Too Low: < 1000
Normal: Between 3000 and 9000
Question Zone: > 12000
Red Flag Zone: > 15000

Missing Reason:
 Unknown
 Not Done

Question Added: 22 JUN 2023

12u

Neutrophils

10^3 per cmm

Range Information
Too Low: < 1000
Normal: Between 1500 and 7000
Question Zone: > 10000
Red Flag Zone: > 12000

Missing Reason:
 Unknown
 Not Done

Question Added: 22 JUN 2023

12v

Lymphocytes

10^3 per cmm

Range Information
Too Low: < 500
Normal: Between 2000 and 8000
Question Zone: > 8000
Red Flag Zone: > 10000

Missing Reason:
 Unknown
 Not Done

Question Added: 22 JUN 2023

Viral Studies

14a

CMV serology Negative Not Done Positive Unknown

Question Added: 01 JAN 2010

14b

CMV PCR Negative Not Done Positive Unknown

Question Added: 01 JAN 2010

14b.i

Date of 1st positive CMV PCR

Missing Reason:
 Unknown

FirstPosCMVPCRDateCode

14b.ii

Was the patient treated with oral anti-CMV therapy in the last 12 months? Yes No Unknown

OralAntiCMVTherapy

14c

EBV serology Negative Not Done Positive Unknown

Question Added: 01 JAN 2010

14d

EBV PCR Negative Not Done Positive Unknown

Question Added: 01 JAN 2010

14d

Date of 1st positive EBV PCR

Missing Reason:
 Unknown

FirstPosEBVPCRDateCode

14d.ii Was the patient treated with oral anti-EBV therapy in the last 12 months?

- Yes
- No
- Unknown

OralAntiEBVTherapy

Events since transplant or last Form 8

15a **Coronary Evaluation** Yes
If yes, complete form 4 No

Question Added: 01 JAN 2005
ANGIOFU

15a.i **Coronary Evaluation Event Date:**

Question Added: 07 OCT 2015
F8ANGDT

15b **Rejection** Yes
If yes, complete form 5 No

Question Added: 01 JAN 2005
REJECTFU

15b.i **Rejection Event Date:**

Question Added: 07 OCT 2015
F8REJDT

15c **Infection** Yes
If yes, complete form 6 No

Question Added: 01 JAN 2005
INFECTFU

15c.i **Infection Event Date:**

Question Added: 07 OCT 2015
F8INFDT

15d **Malignancy/PTLD** Yes
If yes, complete form 7 No

Question Added: 01 JAN 2005
MALIGFU

15d.i **Malignancy Event Date:**

Question Added: 07 OCT 2015
F8MALDT

15e **Coronary Revascularization** Yes
If yes, complete form 9 No

Question Added: 01 JAN 2005
CBGPTCFU

15e.i **Coronary Revascularization Event**

F8CRDT

Date:

Question Added: 07 OCT 2015

15f

Death Yes
 If yes, complete form 10 No

Question Added: 01 JAN 2005
DEADFU

15f.i

Death Event Date:

Question Added: 07 OCT 2015
F8DIEDDT

15g

Retransplantation Yes
 If yes, complete form 1RL, 1T, 2, and 3 No

Question Added: 01 JAN 2005
RETXFU

15g.i

Retransplantation Event Date:

Question Added: 07 OCT 2015
F8RTXDT

15h

Renal Transplant Yes
 If yes, complete form 14 No

Question Added: 01 JAN 2010
RENALFU

15h.i

Renal Transplant Event Date:

Question Added: 07 OCT 2015
F8RTDT

15i

Dialysis Yes
 If yes, complete form 14 No

Question Added: 01 JAN 2010
DIALFU

15i.i

Dialysis Event Date:

Question Added: 07 OCT 2015
F8DIALDT

15i.ii

Acute Dialysis Yes
 No

Question Added: 01 JAN 2010
DXMETHAF

15i.iii

Chronic Dialysis Yes
 No

Question Added: 01 JAN 2010
DXMETHCF

15j Diabetes Requiring Insulin since the last follow-up? Yes No

Select 'Yes' every year at time of annual follow-up if the patient is on insulin for diabetes since last follow-up, even if the insulin start date has not changed since the last follow-up.

Question Added: 01 JAN 2005
INSULFU

15j.i Diabetes Event Date:

Date the patient started insulin. If the patient stopped insulin and restarted, it should be the most recent start date.

Question Added: 07 OCT 2015
F8DIABDT

15k Does the patient have a new tracheostomy since last follow-up? Yes No Unknown

Question Added: 04 NOV 2019
F8TRACH

15l Other major events Yes No

OTHERFU

Question Added: 01 JAN 2005
OTHYNFU

15l.i Other major events Event Date:

Question Added: 07 OCT 2015
F8OTHDT

15m Was the Peds QL survey administrated at the time of this annual follow-up or in the last year? Yes No

Question Added: 08 JUN 2020
F8PQL

15m.i Date of Survey

Question Added: 08 JUN 2020
F8PQL_DT

15m.ii Please enter the reason the survey was not administered

- Administrative/staff omission due to unavailability, time constraints, other
- Center not participating in QoL data collection at this time
- Language barrier
- Not Applicable – follow-up prior to PHTS collection of QoL data
- Patient declined
- Patient too sick
- Unable to contact patient
- Other, specify

F8PQLOSP

Question Added: 08 JUN 2020
F8PQLRSN

Was the Family Impact Scale survey Yes

F8FIS

15n administrated at the time of this annual follow-up or in the last year? No

Question Added: 08 JUN 2020

15n.i Date of Survey

Question Added: 08 JUN 2020
F8FIS_DT

15n.ii Please enter the reason the survey was not administered

- Administrative/staff omission due to unavailability, time constraints, other
- Center not participating in QoL data collection at this time
- Language barrier
- Not Applicable – follow-up prior to PHTS collection of QoL data
- Parent declined
- Patient too sick
- Unable to contact parent
- Other, specify

F8FISOSP

Question Added: 08 JUN 2020
F8FISRSN

16 Wall Motion

- Akinesis LVEFAkinesis
- Normal LVEFNormal
- Dyskinesis LVEFDyskinesis
- Hypokinesis LVEFHypokinesis
- Not interpreted for wall motion abnormalities LVEFWallMotionNotInterpreted
- Unknown LVEFWallMotionUnknown

Question Added: 22 JUN 2023

17 Echo Shortening Fraction

Missing Reason:
 Unknown
 Not Done

Question Added: 22 JUN 2023
EchoShorteningFraction

18 Left Ventricular Ejection Fraction

Range Information
Too Low: < 0
Normal: Between 0 and 100
Question Zone: > 101
Red Flag Zone: > 101

Missing Reason:
 Unknown
 Not Done

Question Added: 22 JUN 2023
LeftVentricularEjectionFraction

19 Hospitalization date

Missing Reason:
 Unknown
 Not Done
 Not Applicable

Question Added: 22 JUN 2023
HospitalizationDate

20 Non-cardiac surgery specify

Missing Reason:
 Unknown
 Not Done
 Not Applicable

Question Added: 22 JUN 2023
NonCardiacSurgerySpecify

21	Non-cardiac surgery date	<input type="text"/>	Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done <input type="radio"/> Not Applicable Question Added: 22 JUN 2023 NonCardiacSurgeryDate
22	Cardiac surgery specify	<input type="text"/>	Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done <input type="radio"/> Not Applicable Question Added: 22 JUN 2023 CardiacSurgerySpecify
23	Cardiac surgery date	<input type="text"/>	Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done <input type="radio"/> Not Applicable Question Added: 22 JUN 2023 CardiacSurgeryDate
24	Cardiac intervention specify	<input type="text"/>	Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done <input type="radio"/> Not Applicable Question Added: 22 JUN 2023 CardiacInterventionSpecify
25	Cardiac intervention date	<input type="text"/>	Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done <input type="radio"/> Not Applicable Question Added: 22 JUN 2023 CardiacInterventionDate
26	Pacemaker date	<input type="text"/>	Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done <input type="radio"/> Not Applicable Question Added: 22 JUN 2023 PacemakerDate
27	Treatment for new arrhythmia specify	<input type="text"/>	Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done <input type="radio"/> Not Applicable Question Added: 22 JUN 2023 TreatmentForNewArrhythmiaSpecify
28	Treatment for new arrhythmia date	<input type="text"/>	Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done <input type="radio"/> Not Applicable Question Added: 22 JUN 2023 TreatmentForNewArrhythmiaDate
29	If this is the first year follow-up, please fill out the following section	<input type="radio"/> This is the first year follow-up - fill out next section <input type="radio"/> This is not the first year follow-up	Question Added: 22 JUN 2023 fu_1styear
29a	Echocardiograms - Index Hospitalization	<input type="text"/>	Echo_1h

Question Added: 22 JUN 2023

29b Echocardiograms -
Remainder of Year

Question Added: 22 JUN 2023
Echo_ry

29c Myocardial Biopsies -
Surveillance (biopsies done per protocol with no concerning symptoms)

Question Added: 22 JUN 2023
MB_S

29d Myocardial Biopsies - For
Cause (biopsies performed due to laboratory findings, symptoms or signs concerning for rejection)

Question Added: 22 JUN 2023
MB_fc

29e Cell Free DNA Test (please
complete the donor derived cell-free DNA collection form)

Question Added: 22 JUN 2023
CF_DNA

29f Strategy Change - Did this Yes
Patient have a change in No
biopsy surveillance strategy

Question Added: 22 JUN 2023
sc_yn

17b Date of 1st Change

Missing Reason:
 Unknown

sc_date

17c Reason for Change Rejection
 New DSA
 Low immunosuppression levels
 Graft dysfunction
 Concern for non-compliance
 Other, specify

sc_reason

17d New biopsy strategy Low Intensity Biopsy Strategy - 3 or less planned biopsies in the first year excluding the annual biopsy
 Medium Intensity Biopsy Strategy - 4 to 5 planned biopsies in the first year excluding the annual biopsy
 High Intensity Biopsy Strategy - Greater than >5 planned in the first year excluding the annual biopsy
 Undefined Biopsy Strategy

sc_new_strategy

- 29g Mitral Regurgitation -**
Please report the degree of mitral regurgitation at the echocardiogram closest to one year post-transplant
- None
 - Trivial
 - Mild
 - Mild-Moderate
 - Moderate
 - Moderate-Severe
 - Severe
 - Unknown

Question Added: 22 JUN 2023
mit_regurg

- 29h Tricuspid Regurgitation -**
Please report the degree of tricuspid regurgitation at the echocardiogram closest to one year post-transplant
- None
 - Trivial
 - Mild
 - Mild-Moderate
 - Moderate
 - Moderate-Severe
 - Severe
 - Unknown

Question Added: 22 JUN 2023
tri_regurg

- 29i Right ventricular (RV) Function - Please report the Right ventricular (RV) function at the echocardiogram closest to one year post-transplant**
- Normal
 - Mild Dysfunction
 - Mild-Moderate Dysfunction
 - Moderate Dysfunction
 - Moderate-Severe Dysfunction
 - Severe Dysfunction
 - Unknown Or Not Quantified

Question Added: 22 JUN 2023
rv_function

Contraception

- 30a Was the patient on contraception prior to the visit?**
- Yes
 - No
 - Unknown

contraception

- 30a.i If yes, what type of contraception?**
- Implant
 - IUD
 - Injection
 - Patch
 - Ring
 - Combined oral contraceptives
 - Progesterone-only pill
 - Other, specify

contracep_type

- 30b Was contraception education provided?**
- Yes
 - No
 - Unknown

contracep_edu

- If not provided, why?**
- Caregiver or patient declined

contracep_eduno

30b.i

- No sufficient time during encounter
- Education provided at a previous visit
- Education planned for future visit
- Education given by other provider
- Other, specify

30c

Select the next action/follow-up:

- None needed, patient not sexually active
- None needed, patient already on contraception
- Referred for contraception
- Contraception prescribed/administered in office
- Other, specify

contracep_nxtact

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