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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

7b 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. If the patient was not seen or was seen outside of the follow up window, please submit the follow up anniversary date.

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

_SRHTU

Missing Reason:
☐ Not Done
☐ Unknown

_SRHT

Question Added: 01
JAN 1996

Calculated

BSA: n/a
BMI: n/a

5

Weight

- ☐ Kilograms
- ☐ Pounds

_SRWTU

Missing Reason:
☐ Not Done
☐ Unknown

_SRWT

Question Added: 01
JAN 1996

6

Were Hemodynamics Performed?

If yes, enter the most representative hemodynamics.

- ☐ Yes
☐ No
☐ Unknown

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

7b

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

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

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

Other endocrine, specify

med_End_Othsp

GI

- | | |
|---|------------------|
| <input type="checkbox"/> H2 blocker | med_H2blocker |
| <input type="checkbox"/> PPI | med_PPI |
| <input type="checkbox"/> Other antacid, specify | med_Otherantacid |

Other antacid, specify

med_Otherantacid_osp

Neuro/Psych

- | | |
|--|----------------------|
| <input type="checkbox"/> Anti-anxiety | med_Antianxiety |
| <input type="checkbox"/> Antidepressant | med_Antidepressant |
| <input type="checkbox"/> Antipsychotic | med_Antipsychotic |
| <input type="checkbox"/> Mood stabilizer | med_Moodstabilizer |
| <input type="checkbox"/> Narcotic (chronic use, not prn) | med_Narcotic_chronic |
| <input type="checkbox"/> Non-stimulant ADHD | med_NonstimulantADHD |
| <input type="checkbox"/> NSAID (chronic use, not prn) | med_NSAID_chronic |
| <input type="checkbox"/> Stimulant ADHD | med_StimulantADHD |
| <input type="checkbox"/> Other neuro-psych, specify | med_Otherneuropsych |

Other neuro-psych, specify

med_Otherneuropsych_osp

Pulmonary

- | | |
|--|--------------------------------|
| <input type="checkbox"/> Inhaled Beta-agonist | med_InhaledBetaagonist |
| <input type="checkbox"/> Inhaled Steroid | med_InhaledSteroid |
| <input type="checkbox"/> Oral Leukotriene inhibitor | med_OralLeukotrieneinhibitor |
| <input type="checkbox"/> Other inhaled bronchodilator, specify | med_Otherinhaledbronchodilator |
| <input type="checkbox"/> Other oral asthma medication, specify | med_Otheroralasthmamed |

Other inhaled bronchodilator, specify

med_Otherinhaledbronch_osp

Other oral asthma medication, specify

med_Otheroralasthmamed_osp

Supplements

- | | |
|--|-----------------------|
| <input type="checkbox"/> Albumin infusion | med_Albumininfusion |
| <input type="checkbox"/> Carnitine | med_Carnitine |
| <input type="checkbox"/> CoQ | med_CoQ |
| <input type="checkbox"/> Pancreatic Enzymes | med_PancreaticEnzymes |
| <input type="checkbox"/> Probiotic | med_Probiotic |
| <input type="checkbox"/> Other supplement, specify | med_Othersupplement |

Other supplement, specify

med_Othersupplement_osp

Immunosuppressants

- | | |
|---|----------------------|
| <input type="checkbox"/> Anakinra | med_Anakinra |
| <input type="checkbox"/> Azathioprine | med_Azathioprine |
| <input type="checkbox"/> Basiliximab | med_Basiliximab |
| <input type="checkbox"/> Cyclophosphamide | med_Cyclophosphamide |
| <input type="checkbox"/> Cyclosporine | med_Cyclosporine |
| <input type="checkbox"/> Everolimus | med_Everolimus |
| <input type="checkbox"/> Immune Globulin | med_ImmuneGlobulin |
| <input type="checkbox"/> Methotrexate | med_Methotrexate |
| <input type="checkbox"/> MMF | med_MMF |
| <input type="checkbox"/> Rituximab | med_Rituximab |
| <input type="checkbox"/> Sirolimus | med_Sirolimus |
| <input type="checkbox"/> Steroids | med_Steroids |
| <input type="checkbox"/> Tacrolimus | med_Tacrolimus |
| <input type="checkbox"/> 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, Nicardipine, 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
- ☐ >18 but did not graduate high school NGSCHLFU

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

PRIINS

- ☐ Self Pay
☐ 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

- ☐ mg/dL
☐ umol/L

Range Information

Too Low: < 0
 Normal: Between 0.3 and 1.2
 Question Zone: > 2.4
 Red Flag Zone: > 10

Missing Reason:

- ☐ Not Done
☐ Unknown

Question Added: 01 JAN 2010

BILTF_U

BILTF

12b

Direct Bilirubin

- ☐ mg/dL
☐ umol/L

Range Information

Too Low: < 0
 Normal: Between 0 and 0.2
 Question Zone: > 0.4
 Red Flag Zone: > 5

Missing Reason:

- ☐ Not Done
☐ Unknown

Question Added: 01 JAN 2010

BILDF_U

BILDF

12c

AST

Aspartate transaminase (also SGOT) U/L

Range Information

Too Low: < 0
 Normal: Between 10 and 60
 Question Zone: > 120
 Red Flag Zone: > 1000

Missing Reason:

- ☐ Not Done
☐ Unknown

Question Added: 01 JAN 2010

ASTF

12d

ALT

Alanine transaminase (also SGPT) U/L

Range Information

Too Low: < 0
 Normal: Between 7 and 45
 Question Zone: > 90
 Red Flag Zone: > 1000

Missing Reason:

- ☐ Not Done
☐ Unknown

Question Added: 01 JAN 2010

ALTF

12e

BNP

B-type natriuretic peptide pg/mL or ng/L

Range Information

Too Low: < 0
 Normal: Between 10 and 100
 Question Zone: > 1000
 Red Flag Zone: > 10000

Missing Reason:

- ☐ Not Done
☐ Unknown

Question Added: 01 JAN 2010

BNPF

12f

Pro BNP

Pro NT B-type natriuretic peptide

- ☐ pg/mL or ng/L
☐ pmol/L

Range Information

Too Low: < 0
 Normal: Between 10 and 300
 Question Zone: > 3000
 Red Flag Zone: > 30000

Missing Reason:

- ☐ Not Done
☐ Unknown

Question Added: 07 OCT 2015

PROBNPF_U

PROBNPF

12g	HbA1c	<input type="text"/>	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
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	<input type="text"/> Blood urea nitrogen <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	<input type="text"/> 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
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	<input type="text"/> Total Cholesterol <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	<input type="text"/> Triglycerides <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	<input type="text"/> Low density lipoprotein <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	<input type="text"/> High density lipoprotein <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	<input type="text"/> Very low density lipoprotein <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
	Hemoglobin	<input type="text"/>	Range Information Too Low: < 6 Normal: Between 8 and 15	Missing Reason:	Question Added: 22 JUN 2023

12r	(gm/dL)	Question Zone: > 16 Red Flag Zone: > 20	<input type="radio"/> Unknown <input type="radio"/> Not Done
12s	Hematocrit	<input type="text"/> Percentage	Range Information Too Low: < 18 Normal: Between 24 and 45 Question Zone: > 46 Red Flag Zone: > 60 Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done
12t	WBC	<input type="text"/> 10^3 per cmm	Range Information Too Low: < 1000 Normal: Between 3000 and 9000 Question Zone: > 12000 Red Flag Zone: > 15000 Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done
12u	Neutrophils	<input type="text"/> 10^3 per cmm	Range Information Too Low: < 1000 Normal: Between 1500 and 7000 Question Zone: > 10000 Red Flag Zone: > 12000 Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done
12v	Lymphocytes	<input type="text"/> 10^3 per cmm	Range Information Too Low: < 500 Normal: Between 2000 and 8000 Question Zone: > 8000 Red Flag Zone: > 10000 Missing Reason: <input type="radio"/> Unknown <input type="radio"/> Not Done

Viral Studies

14a	CMV serology	<input type="radio"/> Negative <input type="radio"/> Not Done <input type="radio"/> Positive <input type="radio"/> Unknown	Question Added: 01 JAN-2010
14b	CMV PCR	<input type="radio"/> Negative <input type="radio"/> Not Done <input type="radio"/> Positive <input type="radio"/> Unknown	Question Added: 01 JAN-2010
14b.i	Date of 1st positive CMV PCR	<input type="text"/>	Missing Reason: <input type="radio"/> Unknown FirstPosCMVPCRDatCode
14b.ii	Was the patient treated with oral anti-CMV therapy in the last 12 months?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	OralAntiCMVTherapy
14c	EBV serology	<input type="radio"/> Negative <input type="radio"/> Not Done <input type="radio"/> Positive <input type="radio"/> Unknown	Question Added: 01 JAN-2010
14d	EBV PCR	<input type="radio"/> Negative <input type="radio"/> Not Done <input type="radio"/> Positive <input type="radio"/> Unknown	Question Added: 01 JAN-2010
14d	Date of 1st positive EBV PCR	<input type="text"/>	Missing Reason: <input type="radio"/> Unknown FirstPosEBVPCRDatCode
Was the patient treated with oral anti-		<input type="radio"/> Yes	OralAntiEBVTherapy

14d.ii EBV therapy in the last 12 months? ☐ No ☐ Unknown

Events since transplant or last Form 8

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

Question Added: 01 JAN 2005
ANGIOFU

15a.i Coronary Evaluation Event Date:

Question Added: 07 OCT 2015
F8ANGDT

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

Question Added: 01 JAN 2005
REJECTFU

15b.i Rejection Event Date:

Question Added: 07 OCT 2015
F8REJDT

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

Question Added: 01 JAN 2005
INFECTFU

15c.i Infection Event Date:

Question Added: 07 OCT 2015
F8INFDT

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

Question Added: 01 JAN 2005
MALIGFU

15d.i Malignancy Event Date:

Question Added: 07 OCT 2015
F8MALDT

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

Question Added: 01 JAN 2005
CBGPTCFU

15e.i Coronary Revascularization Event Date:

Question Added: 07 OCT 2015
F8CRDT

15f

Death ☐ YesIf yes, complete form 10 ☐ NoQuestion Added: 01 JAN 2005
DEADFU

15f.i

Death Event Date:

Question Added: 07 OCT 2015
F8DIEDDT

15g

Retransplantation ☐ YesIf yes, complete form 1RL, 1T, 2, and 3 ☐ NoQuestion Added: 01 JAN 2005
RETXFU

15g.i

Retransplantation Event
Date:Question Added: 07 OCT 2015
F8RTXDT

15h

Renal Transplant ☐ YesIf yes, complete form 14 ☐ NoQuestion Added: 01 JAN 2010
RENALTFU

15h.i

Renal Transplant Event
Date:Question Added: 07 OCT 2015
F8RTDT

15i

Dialysis ☐ YesIf yes, complete form 14 ☐ NoQuestion Added: 01 JAN 2010
DIALFU

15i.i

Dialysis Event Date:

Question Added: 07 OCT 2015
F8DIALDT

15i.ii

Acute Dialysis ☐ Yes☐ NoQuestion Added: 01 JAN 2010
DXMETHAF

15i.iii

Chronic Dialysis ☐ Yes☐ NoQuestion 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

Diabetes Event Date:

Date the patient started insulin. If the patient stopped insulin and

F8DIABDT

15j.i restarted, it should be the most recent start date.

Question Added: 07 OCT 2015

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

15n Was the Family Impact Scale survey administrated at the time of this annual follow-up or in the last year? ☐ Yes ☐ No

Question Added: 08 JUN 2020
F8FIS

15n.i

Date of Survey

Question Added: 08 JUN 2020
F8FIS_DT15n.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

Missing Reason:

- ☐ Unknown
- ☐ Not Done
- ☐ Not Applicable

Question Added: 22 JUN 2023
NonCardiacSurgeryDate

CardiacSurgerySpecify

22	Cardiac surgery specify	<input type="text"/>	Question Added: 22 JUN 2023 Missing Reason: <input type="radio"/> Unknown
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"/>	Question Added: 22 JUN 2023 Echo_1h
29b	Echocardiograms - Remainder of Year	<input type="text"/>	Question Added: 22 JUN 2023 Echo_ry
			Question Added: 22 JUN 2023 MB_S
Myocardial Biopsies - For Cause		<input type="text"/>	MB_fc

29d (biopsies performed due to laboratory findings, symptoms or signs concerning for rejection)

Question Added: 22 JUN 2023

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 Patient have a change in biopsy surveillance strategy

- ☐ Yes
☐ No
☐ Unknown

Please only answer if patient was transplanted AFTER June 20,2023. If patient was transplanted BEFORE June 20 2023, then answer Unknown.

Question Added: 22 JUN 2023
sc_yn

29f.i Date of 1st Change

Missing Reason:
☐ Unknown

sc_date

29f.ii Reason for Change

- ☐ Rejection
☐ New DSA
☐ Low immunosuppression levels
☐ Graft dysfunction
☐ Concern for non-compliance
☐ Other, specify

sc_reason

29f.iii 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

- ☐ None
☐ Trivial
☐ Mild

tri_regurg

the echocardiogram closest to one year post-transplant

- ☐ Mild-Moderate
☐ Moderate
☐ Moderate-Severe
☐ Severe
☐ Unknown

Question Added: 22 JUN 2023

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
☐ Not Applicable

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
☐ Not Applicable

contracep_edu

30b.i If not provided, why?

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

contracep_eduno

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

contracep_nxtact

☐ Other, specify

☐ Not Applicable

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