

SHORT FOLLOW - UP REPORTING FORM

Only Report Data Collected Within 1-week Follow-up 'Window'

Patient Registry for Primary Pulmonary Hypertension
FOLLOW-UP REPORTING FORM

IDENTIFICATION AND DEMOGRAPHIC DATA
PRESENT MEDICAL HISTORY
FAMILY HISTORY AND FAMILY SCREENING RESULTS
PHYSICAL EXAMINATION RESULTS
LABORATORY TEST RESULTS
ETIOLOGY - ADDITIONAL INFORMATION ON DEFINED SUBSETS
HEMODYNAMIC DATA AND HEMODYNAMIC MEASUREMENTS
COMPLICATIONS ARISING FROM A PROCEDURE OR TEST

Please Return to:
PRPPH - PROJECT COORDINATOR
UNIVERSITY OF ILLINOIS, CHICAGO
SCHOOL OF PUBLIC HEALTH - WEST
BOX 6998
CHICAGO, IL 60680

ATTN: CHRISTOPHER M. BARKER M.A., M.S.
[PHONE: (312)-996-8860]

DCC Requests Follow-up Submission At Least Every 6-Months
INVESTIGATOR, PLEASE RETAIN YELLOW COPY
Patient Registry for Primary Pulmonary Hypertension

SHORT FOLLOW - UP REPORTING FORM
IDENTIFICATION AND DEMOGRAPHIC DATA
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VERSION 1.0 (1983)
CORRECTED 11-02-83

ID # () () ()
-Ct. -Pat. -AcPoStTc

1. Identification:

- 1) Institution code: () 2) Patient sequence number ()
3) Patient acrostic ()

2. Date (mo/da/yr) patient last contacted () () 19()

NOTE: The Data on this form should be collected within 1-week of the date of last contact. Please see PRPPH Protocol pages 27+ and the Guidelines on the cover page. Note that the DCC requests Follow-up data AT LEAST once every 6-months. Data collected by a phone contact are acceptable.

3. Date (mo/da/yr) form completed () () 19()

4. Weight () Check units: 1) () kilograms 2) () lbs

5. Please sign below upon completion of the form

Completed by _____ Reviewed by _____

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PRESENT MEDICAL HISTORY
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| VERSION 1.0 (1983) ID # (_) (_ | |) (_ | | | |)
CORRECTED 11-02-83 Ctr. Pat. AcPostic

1. Current symptoms: Enter the number corresponding to the severity (1=most severe, ..., 9=least severe) of the symptom(s).

- 1) (_) Asymptomatic
- 2) (_) Breathlessness
- 3) (_) Chest pain
- 4) (_) Edema, specify location -----
- 5) (_) Fatigue
- 6) (_) Near Syncope
- 7) (_) Palpitations
- 8) (_) Syncope
- 9) (_) Other symptoms, specify -----

2. New symptoms: Enter the number corresponding to the chronological order of appearance of the symptom(s).

- 1) (_) Breathlessness
- 2) (_) Chest pain
- 3) (_) Edema, specify location -----
- 4) (_) Fatigue
- 5) (_) Near Syncope
- 6) (_) None
- 7) (_) Palpitations
- 8) (_) Syncope
- 9) (_) Other symptoms, specify -----

cf. Follow-up MOOP:pp 2.1

cf. PRPPH Protocol:pp 27+

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4) Other medications:

	DRUG	DOSAGE PER DAY	UNITS (**)
1)	_____/_____	_____/_____	_____
2)	_____/_____	_____/_____	_____
3)	_____/_____	_____/_____	_____
4)	_____/_____	_____/_____	_____
5)	_____/_____	_____/_____	_____

(**) Please specify units

5) Related adverse effects:

[] _____

6. List the date(s) and reasons for any hospitalizations since last visit.

	FROM (DATE) Mo. Yr.	TO (DATE) Mo. Yr.	SPECIFY REASON FOR HOSPITALIZATION
1)	(_) 19(____)	(_) 19(____)	[] _____
2)	(_) 19(____)	(_) 19(____)	[] _____
3)	(_) 19(____)	(_) 19(____)	[] _____
4)	(_) 19(____)	(_) 19(____)	[] _____

cf. Follow-up MOOP:pp 2.1

cf. PRPPH Protocol:pp 27+

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7. -- If it now appears that the patients' pul. htn. is related to any of the following, please indicate so and complete section V (Etiology).

A. Cirrhosis

- 1) No
- 2) Yes (complete Etiology section beginning on page 7)

B. Collagen Vascular disease

- 1) No
- 2) Yes (complete Etiology section beginning on page 7)

C. Diet or drug related

- 1) No
- 2) Yes (complete Etiology section beginning on page 7)

cf. Follow-up MOOP:pp 2.1

cf. PRPPH Protocol:pp 27

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INVESTIGATORS PLEASE NOTE:

The follow-up form is to be filled out by the investigator or the person designated by the investigator. It is important that the individual completing the form and the person reviewing the form provide their signature in the space indicated.

TIME PERIOD FOR SUBMISSION:

The follow-up periods are designated in the following way:

First Follow-up period: Begins at the end of baseline reporting period and terminates six months after baseline catheterization.

Second Follow-up period: Begins at the end of the first follow-up reporting period and terminates twelve months after baseline catheterization.

The remaining follow-ups, third through last follow the example of the second follow-up period above.

GUIDELINES FOR DATA SUBMISSION DURING FOLLOW-UP PERIODS:

It is recommended that investigators follow these guidelines. If exceptions arise please notify the Project Coordinator.

Guideline A.: The patient has multiple catheterizations during the follow-up period. Investigator initiates a follow-up form for each catheterization performed during the follow-up period. Additional tests to be reported are those occurring within one (1) week prior and one (1) week following the catheterization.

Guideline B.: Patient is seen or contacted only the end of the six month period. Investigator initiates a follow-up form using information collected from that visit or contact (i.e. telephone call).

Guideline C.: Patient is seen at various times during the follow-up period. A follow-up form is initiated as soon as Identification, Present Medical History, Physical Examination and Hemodynamic Measurements are complete.

In all other situations, please complete as much of the follow-up form as possible during a follow-up period.

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ID # () () ()
 - Ctr. - Pat. - AcPostic

1. Hepatic cirrhosis

- 1) () No
- 2) () Yes,
 (please complete
 the following)

A. Complications
 (e.g. esophageal varices)

- 1) () No
- 2) () Yes, specify:
 [] _____

B. Type of cirrhosis
 (check appropriate answer).

- 1) () Alcoholic
- 2) () Chronic active hepatitis
- 3) () Postnecrotic cirrhosis
- 4) () Primary biliary cirrhosis
- 5) () Hemochromatosis
- 6) () Wilson's disease
- 7) () Alpha-1-antitrypsin
 deficiency
- 8) () Biliary tree obstruction

**2. Associated collagen
 vascular diseases**
 (Please see MOOP).

- 1) () No
- 2) () Yes, Please check if any
 of the following
 diseases are present.

- 1) () Dermatomyositis
- 2) () Hashimoto's thyroiditis
- 3) () Lupus erythematosus
- 4) () Mixed connective
 tissue disease
- 5) () Polymyositis
- 6) () Raynaud's disease
- 7) () Rheumatoid arthritis
- 8) () Scleroderma
- 9) () Other vasculitis,
 specify: [] _____
- 10) () Other immune
 related diseases,
 specify:

[] _____
 [] _____

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3. Other associated illnesses

- _____
- _____
- _____
- _____