

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)-996-8660]

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

FOLLOW - UP REPORTING FORM  
IDENTIFICATION AND DEMOGRAPHIC DATA  
Only Report Data Collected Within 1-week Follow-up 'Window'

VERSION 2.0 (1982)  
CORRECTED 04-01-83

ID # ( ) ( ) ( )  
Ctr. Pat. Acrostic

1. Identification:

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

2. Date (mo/da/yr) patient was 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 \_\_\_\_\_

FOLLOW - UP REPORTING FORM  
PRESENT MEDICAL HISTORY

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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 \_\_\_\_\_



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PRESENT MEDICAL HISTORY

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4) Other medication:

	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( )	[ ] _____

FOLLOW - UP REPORTING FORM  
PRESENT MEDICAL HISTORY

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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)

FOLLOW - UP REPORTING FORM

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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.

FOLLOW - UP REPORTING FORM  
 FAMILY HISTORY AND FAMILY SCREENING RESULTS  
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ID # ( \_ ) ( \_ \_ ) ( \_ \_ \_ \_ )  
 Ctr. Pat. Acrostic

1. Please complete for each member of the patient's immediate family (parents, siblings, children) now being screened by you for primary pulmonary hypertension.

SPECIFY RELATIONSHIP	SCREENED FOR PUL.HTN. N OR Y (IF YES NOTE 1, 2, AND/OR 3 *)	PUL. HTN. SUGGESTED BY 1,2 AND/OR 3 (*) (CIRCLE ONE)
1) _____	( ) 1 2 3	1 2 3
2) _____	( ) 1 2 3	1 2 3
3) _____	( ) 1 2 3	1 2 3
4) _____	( ) 1 2 3	1 2 3
5) _____	( ) 1 2 3	1 2 3
6) _____	( ) 1 2 3	1 2 3
7) _____	( ) 1 2 3	1 2 3
8) _____	( ) 1 2 3	1 2 3
9) _____	( ) 1 2 3	1 2 3
10) _____	( ) 1 2 3	1 2 3

* 1 ecg
2 chest x-ray
3 physical exam



FOLLOW - UP REPORTING FORM  
 PHYSICAL EXAMINATION RESULTS  
 Only Report Data Collected Within 1-week Follow-up 'Window'

VERSION 2.0 (1982)   CORRECTED 04-01-83	ID # ( _ ) ( _ ) ( _ ) ( _ ) ( _ ) Ctr.      Pat.      Acrostic
--	--

1. Vital signs.

- 1) Heart rate ( \_ ) ( \_ ) beats/min
- 2) Blood pressure ( \_ ) ( \_ ) / ( \_ ) ( \_ ) mm hg
- 3) Respiration rate ( \_ ) per minute

2. Chest exam.

A. Abnormal breath sounds:

- 1) ( ) No
- 2) ( ) Yes, please check the following answer:

		RALES	WHEEZES	ABSENT
Right	Apex	1) ( )	2) ( )	3) ( )
	Mid-lung	4) ( )	5) ( )	6) ( )
	Base	7) ( )	8) ( )	9) ( )
Left	Apex	1) ( )	2) ( )	3) ( )
	Mid-lung	4) ( )	5) ( )	6) ( )
	Base	7) ( )	8) ( )	9) ( )

FOLLOW - UP REPORTING FORM  
PHYSICAL EXAMINATION RESULTS

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2. Cardiac exam

A. Jugular

venous pres. ( ) ca H2O

B. Carotid pulse, check answer

- 1) ( ) Normal 2) ( ) Reduced  
3) ( ) Other, specify [ ] \_\_\_\_\_

C. Left ventricular impulse

1. Location (intercostal space)

- 1) ( ) 4th 2) ( ) 5th  
3) ( ) 6th 4) ( ) 7th

2. Character, check answer(s)

- 1) ( ) Normal 2) ( ) Increased  
3) ( ) Diffuse  
4) ( ) Sustained 5) ( ) Dynamic

D. Right ventricular impulse

1. Character, check answer(s)

- 1) ( ) Normal 2) ( ) Increased  
3) ( ) Diffuse  
4) ( ) Sustained 5) ( ) Dynamic

E. Is pulmonic closure palpable

- 1) ( ) No 2) ( ) Yes

F. Heart sounds

1. S1 (check)

- 1) ( ) Normal 2) ( ) Increased  
3) ( ) Decreased

2. S2 (check)

- 1) ( ) Normal 2) ( ) Increased A2  
3) ( ) Decreased A2 4) ( ) Increased P2  
5) ( ) Decreased P2 6) ( ) Fixed split  
7) ( ) Paradoxically split

3. S3 (check)

- 1) ( ) No 2) ( ) Yes  
3) ( ) Right-sided 4) ( ) Left-sided

4. S4 (check)

- 1) ( ) No 2) ( ) Yes  
3) ( ) Right-sided 4) ( ) Left-sided

FOLLOW - UP REPORTING FORM  
PHYSICAL EXAMINATION RESULTS

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3. Cardiac Exam, continued

G. Extra sounds, clicks, rubs, etc. 1)  No 2)  Yes, Specify \_\_\_\_\_

H. Murmurs (check if present):

	APEX	BASE	LEFT STERNAL EDGE
Systolic ejection	1) <input checked="" type="checkbox"/> /6	2) <input type="checkbox"/> /6	3) <input type="checkbox"/> /6
Systolic regurgitation	4) <input checked="" type="checkbox"/> /6	5) <input type="checkbox"/> /6	6) <input type="checkbox"/> /6
Diastolic	7) <input checked="" type="checkbox"/> /4	8) <input type="checkbox"/> /4	9) <input type="checkbox"/> /4

4. Liver span (  ) cm

A. Pulsations 1)  No 2)  Yes

5. Extremities:

A. Peripheral edema 1)  No 2)  Yes, severity (1-4+) \_\_\_\_\_

B. Cyanosis 1)  No 2)  Yes

C. Clubbing 1)  No 2)  Yes

6. Is there any clinical evidence for:

A. Tricuspid regurgitation 1)  No 2)  Yes

B. Mitral regurgitation 1)  No 2)  Yes

C. Pulmonic insufficiency 1)  No 2)  Yes

D. Right-to-left shunting 1)  No 2)  Yes

FOLLOW - UP REPORTING FORM  
LABORATORY TEST RESULTS

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1. Chest X-ray (Please save copies).

A. Cardiothoracic ratio ( )%

B. Pulmonary vasculature

	NORMAL	INCREASE	DECREASE
1. Main PA	1) ( )	2) ( )	3) ( )
2. Hilar vessels	1) ( )	2) ( )	3) ( )
3. Mid-lung vessels	1) ( )	2) ( )	3) ( )
4. Peripheral vessels	1) ( )	2) ( )	3) ( )

	NO	YES
5. Apical redistribution	1) ( )	2) ( )
6. Pruning	1) ( )	2) ( )
7. Other, specify: _____		

C. Lung fields

1) ( ) Normal

2) ( ) Opacities, specify location:

	LOCAL	DIFFUSE
a. Nodular	1) ( )	2) ( )
b. Linear	1) ( )	2) ( )
c. Septal lines	1) ( )	2) ( )
d. Other, please describe		

\_\_\_\_\_

D. Pleural effusion

1) ( ) No

2) ( ) Yes, specify:

1) ( ) Right

2) ( ) Left

E. Additional pertinent findings

2. Electrocardiogram

Please see instruction booklet. Please save copy.

A. Rhythm

- 1)  Sinus 2)  A-fib 3)  A-flutter
- 4)  Other supraventricular
- 5)  Other, please specify \_\_\_\_\_

B. Rate (ventricular):  beats/minute

C. P-R interval (0.) (sec) QRS (0.) (sec)

Q-T (0.) (sec)

D. QRS axis specify

- 1)  PLUS (+)
- 2)  MINUS (-)
- 3) DEGREES

E. Maximum height of P wave () mm

Which lead? \_\_\_\_\_

F. Right ventricular hypertrophy? 1)  No 2)  Yes 3)  Uncertain

G. Right bundle branch block pattern

1)  No 2)  Yes 3)  Uncertain

H. Right ventricular strain pattern?

1)  No 2)  Yes 3)  Uncertain

I. S1, S2, S3 pattern 1)  No 2)  Yes 3)  Uncertain

J. Other abnormalities \_\_\_\_\_

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LABORATORY TEST RESULTS

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3. Hematology.

A. Hemoglobin ( _   _ . _ ) gm%	E. Platelets
B. Hematocrit ( _   _ ) %	1) ( ) Normal
C. Leukocyte count ( _   _ . _ ) /x10 <sup>3</sup> /mm <sup>3</sup>	2) ( ) Abnormal
D. Differential count	3) Absolute count
1) Neutrophils ( _   _ ) %	( _   _   _ ) x10 <sup>3</sup> /mm <sup>3</sup>
2) Lymphocytes ( _   _ ) %	F. Prothrombin time (sec)
3) Monocytes ( _   _ ) %	1) ( _   _ . _ ) sec 2) ( _   _ . _ ) CONTROL
4) Eosinophils ( _   _ ) %	G. ESR mm/hr ( _   _   _ )
5) Basophils ( _   _ ) %	

4. Respiratory function tests (Please report volumes in liters)

A. TLC ( _   _ . _   _ )		
B. PVC ( _   _ . _   _ )		
C. FRC ( _   _ . _   _ )   FRC Technique: 1) ( ) Dilution 2) ( ) Body Box		
D. VE ( _   _ . _   _ ) FREQ ( _   _ . _   _ )		
E. FEV1 ( _   _ . _   _ )		
F. FEV3 ( _   _ . _   _ )		
G. FEF 25-75 ( _   _ . _   _ )		
H. DLCO ( _   _ . _ ) ml/min/Hg ( ) If corrected ,specify, _____		
1. DLCO Technique		
1) ( ) Single Breath 2) ( ) Steady State 3) ( ) Rebreathing		
I. DLCO/VA ( _   _ . _ )		
<u>Arterial blood gases (Room Air)</u>		
J. PaO2 ( _   _   _ ) mm Hg	K. PaCO2 ( _   _   _ ) mm Hg	L. pH ( _ . _   _ )

FOLLOW - UP REPORTING FORM  
LABORATORY TEST RESULTS

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5. Biochemistry (Please see MOOP) .

- A. BUN ( \_ | \_ | \_ ) mg%
- B. Creatinine ( \_ | \_ . \_ ) mg%
- C. Total bilirubin ( \_ | \_ . \_ ) mg%
- D. Alkaline phosphatase ( \_ | \_ | / \_ | \_ | ) mu/ml
- E. SGOT ( \_ | \_ | / \_ | \_ | ) mu/ml
- F. LDH ( \_ | \_ | \_ | / \_ | \_ | ) mu/ml
- G. 1) (  ) No 2) (  ) Yes. Please check if a plasma sample was frozen and stored for possible future tests

6. Plasma protein electrophoresis

- |                                    |  |   |
|------------------------------------|--|---|
| 1) Alpha1 ( _   _ . _ ) g/100 ml   |  | 5) Gamma1 ( _   _ . _ ) g/100 ml        |
| 2) Alpha2 ( _   _ . _ ) g/100 ml   |  | 6) Gamma2 ( _   _ . _ ) g/100 ml        |
| 3) Beta ( _   _ . _ ) g/100 ml     |  | 7) Globulin ( _   _ . _ ) g/100 ml      |
| 4) Fibrinogen ( _   _   ) g/100 ml |  | 8) Serum albumin ( _   _ . _ ) g/100 ml |
|                                    |  |   |
|                                    |  |   |

7. Antinuclear antibody titre

- 1) (  ) Negative 2) (  ) Positive (1: \_ | \_ | \_ | \_ ) | Specify Pattern: | \_ | \_\_\_\_\_
- A. Rheumatoid Factor
  - 1) (  ) Negative 2) (  ) Positive (1: \_ | \_ | \_ | \_ )
- B. LE cells
  - 1) (  ) Present 2) (  ) Absent 3) (  ) Not done

8. Pregnancy test (if appropriate) .

- 1) (  ) Negative 2) (  ) Positive 3) (  ) Not Done

FOLLOW - UP REPORTING FORM  
LABORATORY TEST RESULTS  
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9. Lung ventilation/perfusion scan (please save a copy)

A. Ventilation Scan

- 1)  Normal 2)  Abnormal

B. Perfusion Scan

- 1)  Normal

- 2)  Abnormal, please specify:

a. Type of defects

- 1)  Single

- 2)  Multiple discrete

- 3)  Diffuse, patchy

C. Probability of pulmonary embolism

- 1)  High 2)  Low 3)  Indeterminate

D. Right-to-left shunting

- 1)  No

- 2)  Yes

10. Was (will) an open lung biopsy (be) performed?

- 1)  No 2)  Yes, please give date (M/D/Y)

() () 19()



FOLLOW - UP REPORTING FORM  
LABORATORY TEST RESULTS  
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11. Exercise Test (Please See MOOP)

The patient should be asked to exercise until the point where they would normally stop and rest.

A. Please check 1)  Treadmill 2)  Bicycle

Please list exercise protocol used: | \_ | \_\_\_\_\_

	HEART RATE (BPM)	BLOOD PRESSURE (mm Hg)
B. Control (standing)	1) ( _   _   _ )	2) ( _   _   _ / _   _   _ )
C. Maximal exercise attained	1) ( _   _   _ )	2) ( _   _   _ / _   _   _ )

D. Duration of exercise ( \_ | \_ ) min ( \_ | \_ ) sec

E. Reason for stopping

- 1)  Breathlessness
- 2)  Chest pain
- 3)  Dysrhythmia
- 4)  Fatigue
- 5)  ST depression
- 6)  Syncope
- 7)  Other, specify: \_\_\_\_\_

F. Total METS achieved 1) ( \_ | \_ ) 2)  Not Done

G. Workload 1) ( \_ | \_ | \_ | \_ ) WATTS 2) VO2 | \_ | \_ | \_ | \_ | \_ | \_ | \_ |  
3)  Not Done

FOLLOW - UP REPORTING FORM  
LABORATORY TEST RESULTS

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12. Echocardiograms (please save copies) -

A. M-Mode

1. Measurements

- |                                  |                    |                                |
|----------------------------------|--------------------|--------------------------------|
| 1) LA ( _   _ ) mm               | 2) Ao ( _   _ ) mm | 3) LVIDed ( _   _ ) mm         |
| 4) LVIDes ( _   _ ) mm           |                    | 5) RVID ( _   _ ) mm           |
| 6) Septal thickness ( _   _ ) mm |                    | 7) LVPW thickness ( _   _ ) mm |

2. Check if present

- 1)  Paradoxical septal motion
- 2)  Pulmonic valve systolic notching
- 3)  Pericardial effusion
- 4)  'B' Hump on tricuspid valve

3. Other findings: \_\_\_\_\_

B. 2-D study (see MOOP)

1. Tricuspid regurgitation by contrast?

- 1)  No 2)  Yes 3)  Not tested

2. Right to Left shunting by contrast?

- 1)  No 2)  Yes 3)  Not tested

3. Other findings: \_\_\_\_\_

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 ETIOLOGY - ADDITIONAL INFORMATION ON DEFINED SUBSETS  
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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:

[ ] \_\_\_\_\_  
 [ ] \_\_\_\_\_

FOLLOW - UP REPORTING FORM  
ETIOLOGY - ADDITIONAL INFORMATION ON DEFINED SUBSETS  
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3. Other associated illnesses

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

FOLLOW - UP REPORTING FORM  
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Ctr. Pat. Acrostic

1. Hemoglobin ( \_ . \_ ) g%

2. Check method(s) of oxygen content determination:

- 1)  Don't Know 2)  Co-oximetry
- 3)  Gas chromatography
- 4)  Lexicon
- 5)  pH-PO<sub>2</sub> dissociation curve
- 7)  Van-Slyke
- 8)  Other, specify

3. Method of cardiac output determination:

- 1)  Fick 2)  Green dye
- 3)  Thermodilution

4. If second method is used

- 1)  Fick
- 2)  Green dye
- 3)  Thermodilution

5. If patient was on chronic drug therapy for PPH prior to the cath study, indicate drug, dose and duration. (Use the 4 letter codes below; for drugs not listed use first 3 letters of drug name preceded by the letter 'X').

Drug	Dosage (mg/day)	Duration (mos)
1)   _   _   _   _   _ / /		_
2)   _   _   _   _   _ / /		_
3)   _   _   _   _   _ / /		_
4)   _   _   _   _   _ / /		_
5)   _   _   _   _   _ / /		_
6)   _   _   _   _   _ / /		_
7)   _   _   _   _   _ / /		_
8)   _   _   _   _   _ / /		_
9)   _   _   _   _   _ / /		_

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List of 4 letter abbreviations for vasodilator drugs that have been used in the management of primary pulmonary hypertension

(C A P T) Captopril	(P H E N) Phentolamine
(D I A Z) Diazoxide	(P R A Z) Prazosin
(H Y D R) Hydralazine	(P R G I) Prostacycline
(I S O P) Isoproterenol	(P R G E) Prostaglandin - E
(N I F E) Nifedipine	(T E R B) Terbutaline
(N T G L) Nitroglycerine	(T O L A) Tolazoline
(N T P R) Nitroprusside	(V E R A) Verapamil
(P H X Y) Phenoxybenzamine	(M I N O) Minoxidil

-----+  
PLEASE SEE INSTRUCTION BOOKLET REGARDING THE PROCEDURES  
FOR MAKING HEMODYNAMIC MEASUREMENTS.  
-----+

-----+  
CONTROL HEMODYNAMICS ABBREVIATIONS  
-----+

Pra = right atrial pressure (mm Hg)  
Ppa = pulmonary artery pressure (mm Hg)  
Ppcw = pulmonary capillary wedge pressure (mm Hg)  
Psys = systemic arterial pressure (mm Hg)  
QS = cardiac output (liters/minute)  
PaO2 = systemic arterial oxygen tension (mm Hg)  
PaCO2 = systemic arterial carbon dioxide tension (mm Hg)  
SA content = systemic arterial oxygen (ml/dl)  
PA content = pulmonary arterial oxygen (ml/dl)  
VO2 = Oxygen consumption ml/min  
SYS. Art. PH = Systemic Arterial PH

FOLLOW - UP REPORTING FORM  
HEMODYNAMIC DATA AND HEMODYNAMIC MEASUREMENTS  
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TEST -A- (PANEL I)

	8. <u>Measurements</u>
<u>USE MILITARY TIME</u>	--
1. <u>DATE (M/D/Y)</u> ( _ ) ( _ ) 19 ( _ )	1) Heart rate 1   _   _   _
2. <u>Time drug administered</u> ( _ : _ )	2) Pra (mean) 2   _   _
3. <u>Time of measurement</u> ( _ : _ )	3) Ppa (systolic) 3   _   _   _
<u>If applicable, specify</u>	4) Ppa (diastolic) 4   _   _   _
4. ( ) <u>Control</u>	5) Ppa (mean) 5   _   _   _
<u>If applicable, specify</u>	6) Ppcw (mean) 6   _   _
5. ( ) <u>DRUG TEST</u> [ _ ]	7) Psys (systolic) 7   _   _   _
1) NAME   _   _   _	8) Psys (diastolic) 8   _   _   _
2) DOSE   _   _   _	9) Psys (mean) 9   _   _   _
3) ROUTE   _   _   _	10) Qs. (method 1) 10   _   _ . _   _
<u>If applicable, specify</u>	11) Qs. (method 2) 11   _   _ . _   _
6. ( ) <u>EXERCISE TEST</u>	12) PaO2 12   _   _   _
1) DURATION   _   _   _   -MIN   _   _   _   -SEC	13) PaCO2 13   _   _   _
2) WORK-LOAD   _   _   _	14) Sys. Art. PH 14   _ . _   _   _
3) WORK-LOAD UNITS   _   _   _	15) SA content 15   _   _ . _   _
	16) PA content 16   _   _ . _   _
	17) VO2 17   _   _   _   _
7. <u>Purpose(s) of this study:</u> (Check those which apply)	
1) ( ) Acute drug effectiveness	
2) ( ) Chronic drug effectiveness	
3) ( ) Control hemodynamics	

FOLLOW - UP REPORTING FORM  
HEMODYNAMIC DATA AND HEMODYNAMIC MEASUREMENTS  
Only Report Data Collected Within 1-week Follow-up 'Window'

TEST -A- (PANEL II)

9. PREMEDICATION GIVEN FOR CATH STUDY.

DRUG	DOSE & ROUTE	TIME (MIN.) PRIOR TO STUDY
_____/_____	_____/_____	_____/_____
_____/_____	_____/_____	_____/_____
_____/_____	_____/_____	_____/_____

10. Deleterious effects from catheterization during procedure.

- A.  None |
- B.  Yes, check all that apply below
- 1)  Arrythmia requiring thrapy.
- 2)  Cardiac trauma, specify:  
[ ] \_\_\_\_\_
- 3)  Death
- 4)  Embolic phenomena
- 5)  Hypotension requir. thrapy.
- 6)  Other, specify:[ ] \_\_\_\_\_

11. Deleterious effects of drug testing.

- A.  None
- B.  Yes, check all that apply below
- 1)  Allergic reaction
- 2)  Bradycardia
- 3)  Death
- 4)  Hypotension requir. thrapy.
- 5)  Oliguria
- 6)  Other, specify:[ ] \_\_\_\_\_
- C. When were effects first noted?
- 1)  During Cath 2)  Within 24 hours
- 3)  Prior to discharge

12. Use the following space for additional comments on this test.

[ ] \_\_\_\_\_

[ ] \_\_\_\_\_

[ ] \_\_\_\_\_



FOLLOW - UP REPORTING FORM  
HEMODYNAMIC DATA AND HEMODYNAMIC MEASUREMENTS  
Only Report Data Collected Within 1-week Follow-up 'Window'

TEST -B- (PANEL I)

	<u>8. Measurements</u>
<u>USE MILITARY TIME</u>	
1. <u>DATE (M/D/Y)</u> ( ) ( ) 19( )	1) Heart rate 1
2. <u>Time drug administered</u> ( ): ( )	2) Pra (mean) 2
3. <u>Time of measurement</u> ( ): ( )	3) Ppa (systolic) 3
	4) Ppa (diastolic) 4
<u>If applicable, specify</u>	5) Ppa (mean) 5
4. ( ) <u>Control</u>	6) Ppcw (mean) 6
	7) Psys (systolic) 7
<u>If applicable, specify</u>	8) Psys (diastolic) 8
5. ( ) <u>DRUG TEST</u> ( )	9) Psys (mean) 9
1) NAME	10) Qs. (method 1) 10     .
2) DOSE	11) Qs. (method 2) 11     .
3) ROUTE	12) PaO2 12
	13) PaCO2 13
<u>If applicable, specify</u>	14) Sys. Art. PH 14   .
6. ( ) <u>EXERCISE TEST</u>	15) SA content 15     .
1) DURATION         -MIN         -SEC	16) PA content 16     .
2) WORK-LOAD	17) VO2 17
3) WORK-LOAD UNITS	
<u>7. Purpose(s) of this study:</u> (Check those which apply)	
1) ( ) Acute drug effectiveness	
2) ( ) Chronic drug effectiveness	
3) ( ) Control hemodynamics	

cf. Follow-up MOOP:pp 8.1

cf. PRPPH Protocol:pp 27+

DCC Requests follow-up Submission At Least Every 6-Months  
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Patient Registry for Primary Pulmonary Hypertension

FOLLOW - UP REPORTING FORM  
HEMODYNAMIC DATA AND HEMODYNAMIC MEASUREMENTS  
Only Report Data Collected Within 1-week Follow-up 'Window'

TEST -B- (PANEL II)

9. PREMEDICATION GIVEN FOR CATH STUDY.

DRUG	DOSE & ROUTE	TIME (MIN.) PRIOR TO STUDY
<input type="checkbox"/> _____	<input type="checkbox"/> _____	_____
<input type="checkbox"/> _____	<input type="checkbox"/> _____	_____
<input type="checkbox"/> _____	<input type="checkbox"/> _____	_____

10. Deleterious effects from catheterization during procedure.

- A.  None
- B.  Yes, check all that apply below
- Arrythmia requiring thrapy.
  - Cardiac trauma, specify:  
 \_\_\_\_\_
  - Death
  - Embolic phenomena
  - Hypotension requir. thrapy.
  - Other, specify: [ ] \_\_\_\_\_

11. Deleterious effects of drug testing.

- A.  None
- B.  Yes, check all that apply below
- Allergic reaction
  - Bradycardia
  - Death
  - Hypotension requir. thrapy.
  - Oliguria
  - Other, specify: [ ] \_\_\_\_\_

C. When were effects first noted?

- During Cath
- Within 24 hours
- Prior to discharge

12. Use the following space for additional comments on this test.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

FOLLOW - UP REPORTING FORM  
HEMODYNAMIC DATA AND HEMODYNAMIC MEASUREMENTS  
Only Report Data Collected Within 1-week Follow-up 'Window'

TEST -C- (PANEL I)

	8. Measurements	
<u>USE MILITARY TIME</u>		
1. <u>DATE (M/D/Y)</u> ( ) ( ) 19( )	1) Heart rate	1   _   _   _
2. <u>Time drug administered</u> ( ) : ( )	2) Pra (mean)	2   _   _
3. <u>Time of measurement</u> ( ) : ( )	3) Ppa (systolic)	3   _   _   _
	4) Ppa (diastolic)	4   _   _   _
<u>If applicable, specify</u>	5) Ppa (mean)	5   _   _   _
4. ( ) <u>Control</u>	6) Ppcw (mean)	6   _   _
	7) Psys (systolic)	7   _   _   _
<u>If applicable, specify</u>	8) Psys (diastolic)	8   _   _   _
5. ( ) <u>DRUG TEST</u> [ ]	9) Psys (mean)	9   _   _   _
1) NAME   _   _   _   _	10) Qs. (method 1)	10   _   _   .   _   _
2) DOSE   _   _   _   _	11) Qs. (method 2)	11   _   _   .   _   _
3) ROUTE   _   _   _   _	12) PaO2	12   _   _   _
	13) PaCO2	13   _   _   _
<u>If applicable, specify</u>	14) Sys. Art. PH	14   _   .   _   _   _
6. ( ) <u>EXERCISE TEST</u>	15) SA content	15   _   _   .   _   _
1) DURATION   _   _   _   -MIN   _   _   _   -SEC	16) PA content	16   _   _   .   _   _
2) WORK-LOAD   _   _   _   _	17) VO2	17   _   _   _   _
3) WORK-LOAD UNITS   _   _   _   _		
<u>7. Purpose(s) of this study:</u> (Check those which apply)		
1) ( ) Acute drug effectiveness		
2) ( ) Chronic drug effectiveness		
3) ( ) Control hemodynamics		

cf. Follow-up MOOP:pp 3.1

cf. PRPPH Protocol:pp 27+

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FOLLOW - UP REPORTING FORM  
HEMODYNAMIC DATA AND HEMODYNAMIC MEASUREMENTS  
Only Report Data Collected Within 1-week Follow-up 'Window'

TEST -C- (PANEL II)

9. PREMEDICATION GIVEN FOR CATH STUDY.

DRUG	DOSE & ROUTE	TIME (MIN.) PRIOR TO STUDY
_	_	_
_	_	_
_	_	_

10. Deleterious effects from catheterization during procedure.

- A.  None |
- B.  Yes, check all that apply below
- 1)  Arrythmia requiring thrapy.
- 2)  Cardiac trauma, specify:  
[ ] \_\_\_\_\_
- 3)  Death
- 4)  Embolic phenomena
- 5)  Hypotension requir. thrapy.
- 6)  Other, specify:[ ] \_\_\_\_\_

11. Deleterious effects of drug testing.

- A.  None
- B.  Yes, check all that apply below
- 1)  Allergic reaction
- 2)  Bradycardia
- 3)  Death
- 4)  Hypotension requir. thrapy.
- 5)  Oliguria
- 6)  Other, specify:[ ] \_\_\_\_\_
- C. When were effects first noted?
- 1)  During Cath 2)  Within 24 hours
- 3)  Prior to discharge

12. Use the following space for additional comments on this test.

[ ] \_\_\_\_\_

[ ] \_\_\_\_\_

[ ] \_\_\_\_\_

FOLLOW - UP REPORTING FORM  
HEMODYNAMIC DATA AND HEMODYNAMIC MEASUREMENTS  
Only Report Data Collected Within 1-week Follow-up 'Window'

TEST -D- (PANEL I)

	<u>8. Measurements</u>
<u>USE MILITARY TIME</u>	
1. <u>DATE (M/D/Y)</u> ( _ ) ( _ ) 19( _ )	1) Heart rate 1   _   _   _
2. <u>Time drug administered</u> ( _ : _ )	2) Pra (mean) 2   _   _
3. <u>Time of measurement</u> ( _ : _ )	3) Ppa (systolic) 3   _   _   _
	4) Ppa (diastolic) 4   _   _   _
<u>If applicable, specify</u>	5) Ppa (mean) 5   _   _   _
4. ( ) <u>Control</u>	6) Ppcw (mean) 6   _   _
	7) Psys (systolic) 7   _   _   _
<u>If applicable, specify</u>	8) Psys (diastolic) 8   _   _   _
5. ( ) <u>DRUG TEST</u> [ _ ]	9) Psys (mean) 9   _   _   _
1) NAME   _   _   _   _	10) Qs. (method 1) 10   _   _ .   _
2) DOSE   _   _   _   _	11) Qs. (method 2) 11   _   _ .   _
3) ROUTE   _   _   _   _	12) PaO2 12   _   _   _
	13) PaCO2 13   _   _   _
<u>If applicable, specify</u>	14) Sys. Art. PH 14   _ .   _   _
6. ( ) <u>EXERCISE TEST</u>	15) SA content 15   _   _ .   _
1) DURATION   _   _   _   -MIN   _   _   _   -SEC	16) PA content 16   _   _ .   _
2) WORK-LOAD   _   _   _   _	17) VO2 17   _   _   _   _
3) WORK-LOAD UNITS   _   _   _   _	
<u>7. Purpose(s) of this study:</u> (Check those which apply)	
1) ( ) Acute drug effectiveness	
2) ( ) Chronic drug effectiveness	
3) ( ) Control hemodynamics	

cf. Follow-up MOOP:pp 8.1

cf. PRPPH Protocol:pp 27+

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Patient Registry for Primary Pulmonary Hypertension

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FOLLOW - UP REPORTING FORM  
HEMODYNAMIC DATA AND HEMODYNAMIC MEASUREMENTS  
Only Report Data Collected Within 1-week Follow-up 'Window'

TEST -D- (PANEL II)

9. PREMEDICATION GIVEN FOR CATH STUDY.

DRUG	DOSE & ROUTE	TIME (MIN.) PRIOR TO STUDY
_	_	_
_	_	_
_	_	_

10. Deleterious effects from catheterization during procedure.

- A.  None
- B.  Yes, check all that apply below
- 1)  Arrhythmia requiring thrapy.
- 2)  Cardiac trauma, specify:  
[ ] \_\_\_\_\_
- 3)  Death
- 4)  Embolic phenomena
- 5)  Hypotension requir. thrapy.
- 6)  Other, specify:[ ] \_\_\_\_\_

11. Deleterious effects of drug testing.

- A.  None
- B.  Yes, check all that apply below
- 1)  Allergic reaction
- 2)  Bradycardia
- 3)  Death
- 4)  Hypotension requir. thrapy.
- 5)  Oliguria
- 6)  Other, specify:[ ] \_\_\_\_\_
- C. When were effects first noted?
- 1)  During Cath    2)  Within 24 hours
- 3)  Prior to discharge

12. Use the following space for additional comments on this test.

FOLLOW - UP REPORTING FORM  
HEMODYNAMIC DATA AND HEMODYNAMIC MEASUREMENTS  
Only Report Data Collected Within 1-week Follow-up 'Window'

6. DISCHARGE THERAPY.

Please list below the medical therapy if any, that the patient is being discharged on for treatment of PPH. (Please include anticoagulation, digitalis, diuretics, vasodilators, etc. Do not include drugs for other illnesses, such as antibiotics, vitamins, etc.)

	GENERIC DRUG NAME	DAILY DOSAGE	UNITS
1)	_____ / _____	_____ / _____	_____
2)	_____ / _____	_____ / _____	_____
3)	_____ / _____	_____ / _____	_____
4)	_____ / _____	_____ / _____	_____
5)	_____ / _____	_____ / _____	_____
6)	_____ / _____	_____ / _____	_____
7)	_____ / _____	_____ / _____	_____
8)	_____ / _____	_____ / _____	_____

cf. Follow-up MOOP:pp 8.1

cf. PRPPH Protocol:pp 27+

DCC Requests Follow-up Submission At Least Every 6-Months  
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FOLLOW - UP REPORTING FORM  
HEMODYNAMIC DATA AND HEMODYNAMIC MEASUREMENTS  
Only Report Data Collected Within 1-week Follow-up 'Window'

7. Assessment of discharge drug therapy:

A. Do you feel that current drug therapy has been beneficial to the patient?

1)  No 2)  Yes 3)  Uncertain

B. Please list any symptomatic improvements noted:

1. Reduction in:

- 1)  Breathlessness
- 2)  Chest pains
- 3)  Edema
- 4)  Fatigue
- 5)  Palpitations
- 6)  Syncope/dizziness
- 7)  No improvement

2. Improvement in:

- 1)  Effort tolerance 2)  Lifestyle
- 3)  No improvement

3. Other:

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

8.  Date of Hospital Discharge  
If patient died during this hospital stay,  
 Date of death (Please complete Cause of Death form)

(M/D/Y)      (  ) (  ) 19 (  )



FOLLOW - UP REPORTING FORM  
 COMPLICATIONS ARISING FROM A PROCEDURE OR TEST  
 Only Report Data Collected Within 1-week Follow-up 'Window'

VERSION 2.0 (1982) CORRECTED 04-01-83	ID # ( ) ( ) ( ) Ctr.    Pat.    Acrostic
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Complete this section for each procedure in which complications arose.  
Additional Sections should be Requested from DCC

1. Type of procedure.
- A.  Exercise testing
  - B.  Lung Biospy
  - C.  Other test or procedure, specify \_\_\_\_\_

2. Date of procedure or test (M/D/Y) \_\_\_\_/\_\_\_\_/19\_\_\_\_

3. Complications Encountered (Check appropriate answers).

- |  |   |
|--|---|
| <p>A. <input type="checkbox"/> Cardiac</p> <ul style="list-style-type: none"> <li>1) <input type="checkbox"/> Arrythmia requiring therapy</li> <li>2) <input type="checkbox"/> Hypotension/shock requiring therapy</li> <li>3) <input type="checkbox"/> Pulmonary edema</li> <li>4) <input type="checkbox"/> Right heart failure</li> <li>5) <input type="checkbox"/> Syncope</li> </ul> <p>B. <input type="checkbox"/> Thoracic</p> <ul style="list-style-type: none"> <li>1) <input type="checkbox"/> Pneumothorax requiring therap</li> <li>2) <input type="checkbox"/> Pulmonary embolus</li> <li>3) <input type="checkbox"/> Respiratory failure</li> </ul> | <p>C. <input type="checkbox"/> Infection</p> <ul style="list-style-type: none"> <li>1) <input type="checkbox"/> Pneumonitis</li> <li>2) <input type="checkbox"/> Wound: requiring antibiotics, surgery or prolonged hospitalization</li> <li>3) <input type="checkbox"/> Other significant infection</li> </ul> <p>D. <input type="checkbox"/> Other</p> <ul style="list-style-type: none"> <li>1) <input type="checkbox"/> Bleeding requiring transfusion or surgical intervention</li> <li>2) <input type="checkbox"/> Renal Failure</li> <li>3) <input type="checkbox"/> Other, specify</li> </ul> <p style="margin-left: 40px;">[ ] _____</p> <p style="margin-left: 40px;">[ ] _____</p> <p style="margin-left: 40px;">[ ] _____</p> |
|--|---|

4.  Estimate number of additional days of hospitalization due to this complication

A. \_\_\_\_/\_\_\_\_/\_\_\_\_ days