PHA'S EMPOWERED PATIENT ONLINE TOOLKIT

MEDICAL SUMMARY

UPDATE THIS QUARTERLY. Last updated:_____/_____/_________

CRITICAL HEALTH INFORMATION

THIS PATIENT HAS PULMONARY ARTERIAL HYPERTENSION. *No medications should be stopped nor dosages changed without first consulting this patient's PH-treating physician.*

INFO FOR EMTs:

IMPORTANT DOCUMENTS

PATIENT INFORMATION

Name		Email	
Home #		Cell #	
D.O.B.		Address	

ALLERGIES

EMERGENCY INFORMATION

EMERGENCY	9-1-1	LOCAL EMT -DIRECT LINE	
PH-TREATING PHYSICIAN		OFFICE #	
INSTITUTION		DOCTOR-ON-CALL #	
SPECIALTY PHARMACY		HELPLINE #	
PRIMARY CARE PROVIDER		OFFICE #	
AFFILIATED HOSPITAL		HOSPITAL #	
PERSONAL CONTACT		CONTACT #	

HEALTH CONDITIONS

Pulmonary arterial hypertension (PAH)	Date dx:	Condition:	Date dx:
Condition:	Date dx:	Condition:	Date dx:
Condition:	Date dx:	Condition:	Date dx:

CURRENT MEDICATIONS (also see Medication List)

Rx:	Dosage/Amt per day:	Rx:	Dosage/Amt per day:
Rx:	Dosage/Amt per day:	Rx:	Dosage/Amt per day:
Rx:	Dosage/Amt per day:	Rx:	Dosage/Amt per day:

PAST SURGERIES

EMERGENCY CHECKLIST

Your emergency kit is your first line of defense in case of emergency. This checklist includes some common "must haves," but be sure to consult with your doctor, nurse and pharmacist to ensure that you have all the items on hand you need.

- ☐ Emergency contact list
- ☐ Doctor's note to emergency personnel
- ☐ Prescription list
- ☐ Medications
- ☐ Medicine supplies (pumps, inhalers, syringes, needles, batteries, valves, extension tubing, alcohol pads, and all cleaning supplies)
- ☐ Thermometer
- ☐ Blood pressure monitor
- ☐ Cell phone (include your emergency contact's phone number under "In Case of Emergency" or ICE)
- ☐ Medical Alert bracelet

- ☐ Overnight bag containing:
  - ☐ Basic toiletries
  - ☐ Loose-fitting, comfortable change of clothes
  - ☐ Pajamas or nightgown
  - ☐ Slippers or slip-on shoes

Other items:

- ☐ ________________________________
- ☐ ________________________________
- ☐ ________________________________
- ☐ ________________________________
- ☐ ________________________________

If you're on infused medication:

- ☐ Back-up pump
- ☐ Catheter site supplies (gloves, mask, alcohol pads, scrub, dressings, tape, etc.)
- ☐ Site pain supplies
- ☐ Portable cooler (if you must refrigerate your medicine)
- ☐ Ice packs (if you must refrigerate your medicine)

If you use oxygen:

- ☐ Oxygen information
- ☐ Back-up oxygen tanks
- ☐ Oxygen regulator
- ☐ Oxygen tank tool
- ☐ Tank cart
- ☐ Nasal cannula
- ☐ Portable liquid oxygen
- ☐ Portable oxygen concentrator
- ☐ C-Pap or Bi-Pap machine

MEDICATION LIST

MEDICATION NAME	STRENGTH OF EACH DOSE	DOSES AT A TIME	FREQUENCY	PRESCRIBER	START DATE	STOP DATE
Example: Amoxicillin	250 mg	1 pill	3 times daily	Dr. Jones 310-225-5565	5/3/2011	5/17/2011

MEDICAL CONTACT LIST

MEDICAL TEAM CONTACTS

Type of Care	Name	Address	Phone	Fax	Email	Affiliated Hospital
Pulmonary Hypertension	Doctor: Nurse:					
Primary Care						
Specialty Care						
Specialty Care						
Specialty Care						
Specialty Care						

OTHER CONTACTS

Pharmacy	Contact name	Address	Helpline	Phone	Fax	Email
Oxygen Vendor						
Lab						
Durable Medical Equipment						

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INSURANCE FORM

IMPORTANT DOCUMENTS

PRIMARY INSURANCE INFORMATION

Carrier		Group #		Customer Service #		Plan Year Start/Stop Date	
ID #		Plan Type (ex. PPO, HMO, etc.)		Case Manager #		What do I use this for?	

SECONDARY INSURANCE INFORMATION

Carrier		Group #		Customer Service #		Plan Year Start/Stop Date	
ID #		Plan Type (ex. PPO, HMO, etc.)		Case Manager #		What do I use this for?	

PRIVATE PRESCRIPTION PLAN OR MEDICARE PART D INFORMATION

Carrier		Group #		Customer Service #		Plan Year Start/Stop Date	
ID #		Phone #		Case Manager #		Pharmacy #	
Private Plan Name/Medicare Part D Plan				Notes:			

ORIGINAL MEDICARE AND MEDIGAP INFORMATION

Medicare Carrier		Medicare Group #		Phone #		Medicare Case Manager #	
Medicare Claim #		Medicare Type/Part[A, B]		Medicare Customer Service #		Plan Year Start/Stop Date	

Medigap Carrier		Medigap Group #		Medigap Case Manager #		Plan Year Start/Stop Date	
Medigap Claim #		Medigap Type/Part[A, B]		Medigap Customer Service #			
Notes:							

MEDICARE PRIVATE PLAN (PART C) INFORMATION

Carrier		Group #		Phone #		Case Manager #	
Claim #		Plan Name		Customer Service #		Plan Year Start/Stop Date	

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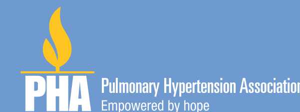

WEEKLY SYMPTOM TRACKER

Use this worksheet to make notes about any symptoms or weight fluctuation you may experience between doctors' visits. Make sure you share this information with your healthcare provider. Together, you can review your progress and make sure you're getting the most out of your treatment plan.

If you experience any unexpected weight gain or worsening of symptoms, contact your pulmonary hypertension team immediately.

For the week of: ______/______/________

Day	Symptoms (swelling, shortness of breath, etc.)	How much did these symptoms bother you?	What foods did you eat today?	What fluids did you drink today?	Weight
Sunday					
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					

QUESTIONS AND NOTES

QUESTIONS TO ASK YOUR MEDICAL TEAM

DURING YOUR INITIAL INTERVIEW WITH A PH-TREATING DOCTOR

- ☐ What year did you begin caring for patients with PH?
- ☐ How many PH patients do you currently treat?
- ☐ Do you have at least one nurse who works with patients on PH-specific medications?
- ☐ Do you require all patients to undergo right heart catheterization with vasodilator testing prior to prescribing a therapy for PH?
- ☐ What PH therapies do you prescribe, and how many patients are on IV prostacyclin?
- ☐ Do you conduct clinical trials on PH medications?
- ☐ Have you referred patients for lung or heart/lung transplant?
- ☐ Have you referred patients for pulmonary thromboendarterectomy?
- ☐ Which educational meetings regarding PH have you attended in the last two years?

AT YOUR FIRST APPOINTMENT

- ☐ How often should I come to see you?
- ☐ How often do I need to have cardiac catheterization?
- ☐ What are the potential side effects of my medication?
- ☐ (If you wear a pump for intravenous medication) What do I do if the line leaks or comes out?
- ☐ What lifestyle changes (nutrition, exercise, etc.) do I need to make?
- ☐ How will you track my progress?

BEFORE TESTS, PROCEDURES, AND ANY CHANGES TO YOUR TREATMENT PLAN

- ☐ What is this test/procedure/medication?
- ☐ Why do I need it?
- ☐ What will be done during the test?
- ☐ How will the test results change how you treat me?
- ☐ How often will I need to have it done?
- ☐ What are the potential complications and side effects?

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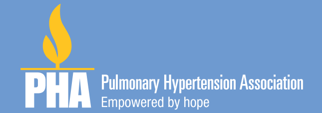

QUESTION TRACKER

USE THIS WORKSHEET TO KEEP TRACK OF NON-URGENT QUESTIONS BETWEEN APPOINTMENTS. AT YOUR NEXT APPOINTMENT, TAKE NOTES ON YOUR DOCTOR'S ANSWERS IN THE SPACE PROVIDED.

Question: ____

____

Answer: ____

____

____

Question: ____

____

Answer: ____

____

____

Question: ____

____

Answer: ____

____

____

DON'T WAIT UNTIL YOUR NEXT APPOINTMENT TO ASK PRESSING QUESTIONS ABOUT NEW SYMPTOMS, SIDE EFFECTS OR YOUR TREATMENT PLAN. WHEN IN DOUBT, CALL YOUR DOCTOR RIGHT AWAY.

QUESTIONS AND NOTES

PREPARING FOR A DOCTOR'S APPOINTMENT

Are there any unanswered questions from our last appointment?

What questions have come up since my last appointment?

How have I been feeling since my last appointment? What symptoms and side effects have I been experiencing?

Are there any other events or changes I want to remember to tell the doctor?

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APPOINTMENT SUMMARY WORKSHEET

FILL THIS OUT WITH YOUR MEDICAL TEAM AFTER YOUR APPOINTMENT. MAKE COPIES FOR YOUR OTHER DOCTORS TO KEEP THEM UP-TO-DATE.

Date: ______________________ Physician: ______________________

Reason for appointment:

____

____

Any changes to treatment plan? ☐ No ☐ Yes (describe below)

____

____

____

Other important notes:

____

____

____

Date of next appointment: ______________________

QUESTIONS AND NOTES

FAMILY HISTORY FORM

Patient Name: ____________ Last Updated: ____________ Date of Birth: ____________

Sex: ______ Ethnicity: ____________ Occupation: ____________

Street Address: ____________ City, State ______ Zip Code ______ Phone Number: ____________

Spouse/Partner Name: ____________ Date of Birth: ____________ Sex: ______ Ethnicity: ____________

Biological Brothers/Sisters and their Children

Sibling Name	Date of Birth	Sex	Current Health	Children (age & sex)

Biological Mother Name: ____________ Maiden Name: ____________

Date and Place of Birth: ____________ Ethnicity: ____________

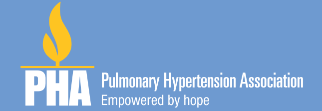
Current Health/Health Problems: ____________

If deceased, age at death and cause: ____________

Mother's Siblings and their Children

Sibling Name	Date of Birth	Sex	Current Health	Children (age & sex)

MEDICAL RECORDS



FAMILY HISTORY FORM II

Maternal Grandfather Name: ____________________ Ethnicity: ____________________

Date and Place of Birth: ____________________ Number of Brothers: ______ Number of Sisters: ______

Current Health/Health Problems: ____________________

If deceased, age at death and cause: ____________________

Maternal Grandmother Name: ____________________ Ethnicity: ____________________

Date and Place of Birth: ____________________ Number of Brothers: ______ Number of Sisters: ______

Current Health/Health Problems: ____________________

If deceased, age at death and cause: ____________________

Are there any other health concerns on the maternal side of the family not yet mentioned? ____________________

____

Biological Father Name: ____________________ Family Name: ____________________

Date and Place of Birth: ____________________ Ethnicity: ____________________

Current Health/Health Problems: ____________________

If deceased, age at death and cause: ____________________

Father's Siblings and their Children

Sibling Name	Date of Birth	Sex	Current Health	Children (age & sex)

MEDICAL RECORDS

FAMILY HISTORY FORM III

Paternal Grandfather Name: ______________________ Ethnicity: ______________________

Date and Place of Birth: ______________________ Number of Brothers: ______ Number of Sisters: ______

Current Health/Health Problems: ______________________

If deceased, age at death and cause: ______________________

Paternal Grandmother Name: ______________________ Ethnicity: ______________________

Date and Place of Birth: ______________________ Number of Brothers: ______ Number of Sisters: ______

Current Health/Health Problems: ______________________

If deceased, age at death and cause: ______________________

Are there any other health concerns on the paternal side of the family not yet mentioned? ______________________

____

Additional notes: ______________________

MEDICAL RECORDS

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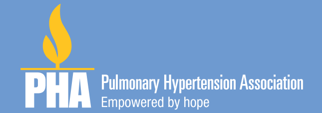
HOSPITAL AND PROCEDURE LOG

Date(s)	Hospital	Physician	Procedure/Reason	Notes

MEDICAL RECORDS



TRAVEL CONTACT LIST

Travel Destination:______________________________________

LOCAL EMERGENCY INFORMATION FOR TRAVEL DESTINATION

Contact	Name	Address	Phone	Fax	Email	Affiliated Hospital
Closest PH center						
Local pharmacy (24 hour if possible)						
Hospital						
EMT/Ambulance						
Other						
Specialty Care						

EMERGENCY INFORMATION FOR MEDICAL CONTACTS AT HOME

Contact	Name	Address	Emergency/On-call	Phone	Fax	Email
PH-treating physician						
Primary care physician						
Specialty pharmacy						
Community pharmacy						
Other						

TRAVEL

TRAVEL CHECKLIST

- ☐ Talk to your pulmonary hypertension doctor to find out if there are any reasons you should not travel at this time.
- ☐ Talk to your PH doctor about any special considerations you should take while traveling, such as the need for supplemental oxygen (even if you don't normally require it), the amount of medications and supplies that should be packed, and the altitude during travel (if flying) and at the travel destination.
- ☐ Ask your PH specialist to write a letter describing your specific medical requirements to simplify the process of obtaining oxygen and bringing medications and supplies through security checkpoints.
- ☐ Before buying any airline, cruise or tour tickets, check with all companies involved to make sure the trip is possible given your medical considerations and needs.
- ☐ When making reservations, consider requesting special arrangements to ensure comfort in transit. For example, using a wheelchair can be helpful to your caregiver and ensures you priority treatment at check points.
- ☐ Consider travel insurance for protection against flight cancellations, lost baggage, etc.
- ☐ Locate a PH specialist close to your travel destination in case of emergency.
- ☐ Plan ahead by ordering your medications before your trip. Let your specialty pharmacy know that you'll be traveling and arrange to have them send your medication directly to your travel destination. Confirm with your hotel that your medication has arrived before you depart.
- ☐ Consider having your routine blood test done before your trip.
- ☐ Pack important documents in your carry-on, including insurance information, a full list of your medications and dosages, specialty pharmacy and medical contacts, and — if you're on IV medication — emergency instructions for how to operate your pump.
- ☐ Pack your PH medications and any other must-have medical supplies in your carry-on bag, not the bag you check. Keep your medications in their original pharmacy bottles
- ☐ If using supplemental oxygen, pack extra oxygen tubing and extra batteries.
- ☐ For longer trips, pack an extra week's worth of medication beyond the intended duration of the trip.
- ☐ If you're on epoprostenol (Flolan), make plans to travel with a small ice chest with 6 to 8 ice packs and a premixed dose of epoprostenol.
- ☐ If on epoprostenol or treprostinil (Remodulin), pack an extra pump.
- ☐ If traveling out of the country, check in advance to determine if there are any laws against bringing medical supplies into a specific country or if special documents are needed.
- ☐ Contact any airlines, cruise lines, etc. in advance to learn if any special requirements or procedures are necessary to administer your PH medications, including oxygen (see below).
- ☐ If a non-stop flight is unavailable, and continuous use of oxygen is needed, arrange for portable oxygen for use at connecting airports or during layovers.
- ☐ Call airlines, cruise lines, tour companies, hotels, oxygen suppliers, etc. 48 hours before leaving to confirm your plans.

If you're planning to use supplemental oxygen in flight on any leg of your journey, call the airline well in advance (at least 2-3 weeks) to ask them the following questions:

- ☐ Is oxygen permitted on board? If so, are there any requirements for bringing oxygen on board? *Most complying airlines require that patients provide their physician's letter to the air carrier in advance of the flight. Patient should inquire about how much advance time they require if the airline does not volunteer this information.*
- ☐ Does the travel carrier offer oxygen?
- ☐ What oxygen system, oxygen flow rates, and delivery devices (e.g. nasal cannula, masks, etc.) are available?
- ☐ Which portable concentrators are allowed to be used in-flight?
- ☐ How much advance notice is required to arrange for oxygen?
- ☐ What is the charge to the traveler? (This cost may not be covered by insurers.)
- ☐ What assistance, if any, is available during transit (e.g. wheelchairs, handicapped access, baggage handling)?

TRAVEL

NOTES