

## Communicating and advocating in a PH emergency

St. Paul, Minn. 2017 PHA on the Road



### Session Description

In this session, we will focus on providing strategies that PH patients and their families can use to optimize medical care during a “PH emergency.” This session aims to educate attendees on common symptoms of a PH emergency, causes of a PH emergency and when to call your PH doctor. We will discuss how to be proactive and prepared to minimize the impact of emergencies or — better yet — avoid them altogether. Join us as we discuss strategies to improve navigation through the emergency department, and develop good communication skills, for any PH emergency to ensure that care is consistent and aligned with the goals and wishes of the PH patient.

### Learning Objectives

Attendees will be able to:

- Define “PH Emergency,” and understand why immediate action is critical
- Know when to contact their PH doctor to prevent or treat a PH Emergency
- Develop a plan to convey important information about PH and medications to emergency responders and hospital physicians
- Advocate for themselves or their family members during the management of a PH emergency

### What is a “PH Emergency?”

- Sudden worsening of pulmonary hypertension that can lead to rapid decline in heart function, organ failure and even death
- Common symptoms can include: confusion, low blood pressure or oxygen levels, shortness of breath, syncope (“passing out”), chest pain and abnormal heart beat
- It is never inappropriate to seek urgent emergency department (ED) evaluation for such symptoms, even for patients who do not have PH.
- In some cases, an urgent situation might be handled better outside the ED – for example infusion pump problems can sometimes be addressed by a call to the PH clinic or specialty pharmacy nurses. Make sure you know who to contact for pump problems if you are on continuous infusion prostacyclin therapy and keep the phone numbers where you can access them.
- Common causes of a “PH Emergency” include:
  - Failure or interruption of PH medications
  - Fluid overload
  - New infection
  - Abnormal heart rhythms
  - Blood clots
  - New anemia or bleeding
- In some cases, surgical procedures or pregnancy can lead to a PH emergency
  - **Immediate** medical attention is required, and a PH specialist should be involved
  - **A PH Emergency can happen anywhere, always be prepared!**

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### **When do I call my PH doctor?**

- For the sudden onset of any symptoms described above; your doctor can help to decide the best way to get you medical attention
- For severe shortness of breath or syncope, call 911 and then call your PH doctor
- For patients using continuous infusions (IV or subcutaneous) of prostacyclin medicines, you should call your doctor immediately for any problems with the IV, pump or medication.
- If you are developing progressive symptoms, including weight gain (more than 4 pounds in a week or 2 pounds in a day)
- Well before you run out of your PH medications or if you need a refill
- Well in advance of any planned surgeries
- As soon as you know that you are pregnant

### **What should I do if I end up in the emergency department?**

Careful preparation lets you do the one thing you probably can't do very well during an emergency – think clearly. Here are some things that can be done ahead of time:

- Make a check list of to-do's
- Many times, you will have care delivered for non-PH related issues in hospitals without a PH specialist. You must be equipped and ready to advocate on your own behalf.
- Be proactive. Most emergencies occur in your locality because that's where you spend most time. Go to the local ED and EMT headquarters and provide them with a basic summary handout of your condition and medications (a link to the pertinent PHA website pages would likely also prove useful). Carry the address links to the PHA pages listed below in your wallet/purse and smartphone.
  - <https://phassociation.org/patients/treatments/>
  - <https://phassociation.org/patients/aboutph/>
- Know your medications inside and out
  - Keep a typed updated list of medications, and post a copy conspicuously in your home (e.g. the refrigerator door)
  - Carry with you a concise list of active diagnoses or conditions (have this list be noticeable in case of an emergency), preferably laminated.
  - Better yet, make sure your health information is accessible on your smartphone!
    - iPhone has a "Health" app which you can set up to let anyone access your locked screen and you can fill it in with medical history, current meds, etc. A button labeled "emergency" on the lock screen give people an option to dial 911 or access the health records on the phone (EMT and ER professionals are trained to look for this app).
    - You might find it helpful to share how to access the information electronically with a trusted family member or healthcare advocate as well.
- Have a small stockpile of necessary medications and supplies (ice packs, inhalation devices used to administer medications and pump- if you are on prostacyclin therapy) in

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a packet ready to go out the door with you in an emergency. Include package inserts for the PH medications so that they will be readily available to emergency personnel and doctors.

- Make sure you know whom to contact for pump problems if you are on IV or SQ prostacyclin therapy. In most cases, contact information is immediately available on the side of the pump. Have a back-up pump at all times.
- If you are being taken to ED by transportation other than ambulance, call ahead.
- Carry with you a list of important contacts: significant others, PH nurse specialist, PH doctor, primary caregiver, specialty pharmacy and others involved in care. You can also program emergency contacts into your cell-phone which EMTs can find and use.
- In an emergency, give the emergency caregivers a clear concise explanation of your diagnosis and situation. Let them get a handle on the situation. But also give them direction (e.g. do not interrupt prostacyclin infusion, if necessary transfer to a peripheral IV and attach your pump).
- **Don't be afraid to remind the emergency providers that your IV PH medications cannot be stopped or changed for any reason. Ask them to call your PH specialist to discuss changes to any of your other PH medications.**
- Ask your doctor if it is appropriate for you to be transferred to the hospital where your PH specialist works.
- Don't forget. Not every problem in a PH patient is due to PH. A thorough review of all possibilities should not be neglected.

### ***How do I advocate for myself or my family member during a PH emergency, so that my/his/her personal wishes/goals are being respected?***

- Discuss your wishes with a trusted family member in advance; know who will be designated to make important decisions for you if you are too sick to make them yourself
- Make this person your appointed health care agent or durable power of attorney (DPOA), which helps your doctors to know that this advocate is speaking with your expressed interests at heart.
- Talk about the status of your PH regularly with your PH doctor. If your disease is worsening despite medications, are there non-medical options for additional treatment that would be appropriate in your case? Would these options be consistent with your overall goals/wishes?