



## ACTION PLAN FOR PH PARENTS: INITIAL SCHOOL CONTACT

The following is a list of steps to consider when starting the initial contact with your child's school to ensure all medical and academic needs are being supported.

- Meet with school staff to educate them about PH. You will want to discuss the following: possible symptoms, how having PH could impact your child's education/school year, current medications, and what to do in a medical emergency.
- Request that an IEP (Individual Education Plan) be considered by school support staff.
- Discuss the medical safety plan with school administration to ensure immediate action should it be required.

### Resources to consider having for school staff

- Introduction Letter- a template letter is provided by PHA Canada, which can be personalized with your child's information.
- Drug Information Sheets (a sheet for each medication is included in this resource; include only those relevant to your child).
- Medical Contact Information:
  - Doctor
  - PH Nurse
- Emergency Information Plan:
  - When to call, who to call and hospital preference.
- List of health and safety guidelines that must be followed when your child is at school:





## GUIDELINES FOR CHILDREN AT SCHOOL

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- Children with PH must drink lots of liquids. While they are at school, they should keep a water bottle on their desk so they can drink throughout the day.
- Some children with PH may not tolerate being outside when the weather is cold, hot or humid as it may affect their breathing. They may need to stay indoors during lunch and/or recess times.
- Special washroom privileges may be needed for some children who are taking water pills (diuretics). They may experience diarrhea as a side effect of their medication. They must be allowed to go to the washroom as often as necessary.
- Children with PH may not be able to participate in all physical activities and may require modifications during Physical Education classes. Alternate activities may need to be provided. A meeting at the school with the student, parent and/ or caregiver to discuss appropriate alternate activities during gym time may be necessary.





## PULMONARY HYPERTENSION INFORMATION FOR STAFF

Student name : \_\_\_\_\_

Parent(s)/Guardian(s) Contact Information:

Coordonnées des professionnels des soins de santé :

Doctor : \_\_\_\_\_

PH Nurse : \_\_\_\_\_

### Emergency Information Plan:

When to call, who to call and hospital preference:

Health and safety guidelines to follow when child is at school:



This resource was designed by the Pediatric Committee of PHA Canada to help you keep track of what to do when your child is diagnosed with PH. Below you will find a double-sided bookmark to print, cut out and keep at hand.

**Instructions:** Print the following two pages on both sides of a sheet of paper (preferably cardstock or photo-paper). Cut along the dotted lines. Keep the bookmark at hand.

(FRONT)



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## To Do Checklist

### When Your Child is Diagnosed with Pulmonary Hypertension:

\* **Make a written list of all your questions. You may also want to take notes when the doctors and nurses answer them.** When a doctor wants to order a test, procedure, or new medication the following questions should be asked:

- What is the test, procedure or medication?
- Why is it needed?
- What will be done during the test?
- How will the test results change how you treat my child?
- How often might the test be required?
- What are the possible complications and/or side effects?
- How will the test results affect the treatment of my child?

\* **Keep an up-to-date Medical Summary** indicating procedures and surgeries your child has had. Keep upcoming appointments in binder.

\* **Make a list of ALL medications being taken.** Include the name of your child's medication, dosage, frequency, reason for taking, when the medication was started and the prescribing physician. Call the pharmacy to renew your child's prescription at least 1 to 1 ½ weeks prior to medication running out, especially if there are no refills left indicated on the vial.

\* **Keep a written list of all your child's doctors and their contact information.** Take this with you to appointments.

(BACK)



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\* **Educate yourself about drug coverage.** Drug coverage for children with PH varies from that for adults. Working with a hospital social worker or the nurses in your child's PH clinic can help to answer questions such as: what will the province cover, what additional programs are available and where to find additional assistance.

\* **Connect with others.** Connect with the Pulmonary Hypertension Association of Canada and find a community of other parents and children living with PH who have experienced or are experiencing the same situation as you and understand what you and your child are going through. [www.facebook.com/PHACanada](http://www.facebook.com/PHACanada)

\* **Get Support.** Join PHA Canada by going to [www.phacanada.ca](http://www.phacanada.ca). PHA Canada provides education and support regarding pulmonary hypertension. We can help to learn about PH, connect you with local support groups, share your story and meet other parents. You are not alone. PHA Canada can be reached reach at:  
**1-877-7-PHACAN (1-877-774-2226)**

This resource was developed by the Pediatric Committee of PHA Canada [www.phacanada.ca](http://www.phacanada.ca). Some of the information has been adapted, with permission, from materials created by PHA USA [www.phassociation.org](http://www.phassociation.org).