

Date: _____

Dear Principal _____:

This letter is to inform you that _____ has a disease called pulmonary arterial hypertension (PAH) (sometimes called pulmonary hypertension (PH)). PAH is a rare disorder characterized by high blood pressure in the lungs. Children with PAH will have varying degrees of symptoms, including:

- Fatigue, dizziness, fainting
- Exercise intolerance or shortness of breath during activity
- Nausea, loss of appetite
- Fluid retention, swelling in the face, ankles, and hands

The school should call 911 for immediate medical services should any of the following symptoms be observed and continue to worsen:

- **Severe chest pain**
- **Fainting**
- **Difficulty breathing**
- **Shortness of breath, accompanied by bluish-purple or very pale lips**

The school should contact the parent(s) or other emergency contact if:

- The child has unusual bluish-purple discoloration of lips/nailbeds
- The child is feeling dizzy or has a headache
- Other _____

There is no cure for PAH. However, there are several effective medications used to treat the disease that may be taken orally, inhaled, or by constant subcutaneous or intravenous infusion. Children may also need oxygen therapy during the day or at night when they are sleeping.

Regular attendance at school may be interrupted because of fatigue, illness, medical appointments, or hospitalizations. Cold and flu season is a time of significant risk for children with PAH and may result in critical illness. Therefore, students with PAH may benefit from an Individual Education Plan (IEP) to ensure their success at school.

It is important that all staff in the school community be educated about the medical condition of _____. Included with this letter is a resource package to provide more specific information about pulmonary arterial hypertension and how best to support children with PAH in the school environment.

Thank you for your support.

Sincerely,

This resource was developed by the Pediatric Committee of PHA Canada. Some of the information has been adapted, with permission, from materials created by PHA USA