

PEDIATRIC

PULMONARY HYPERTENSION

A guide to resources for
parents and families



Pulmonary Hypertension Association
Empowered by hope

This introductory guide was created by the Pulmonary Hypertension Association (PHA) for **parents and families of infants, children and teenagers** with pulmonary hypertension (PH). It gives an overview of PHA resources intended to help your family begin to navigate your child's journey with PH.

Visit PHA's Pediatric Resource Center online at www.PHAssociation.org/PHA-Pediatrics.

Contact PHA by email at KidsWithPH@PHAssociation.org or call (301) 565-3004 x758.

Understanding Pediatric PH

Children, like adults, may develop PH for a number of reasons. One type of PH is unique to newborns whose blood vessels in the lungs do not relax right away as expected after birth. Other children may develop PH due to congenital heart disease or lung diseases. Sometimes PH is genetic and sometimes physicians are not able to identify a specific cause (this is called idiopathic PH).



To learn more about what causes pulmonary hypertension in children and the types of treatment available, visit www.PHAssociation.org/parents/FAQ.

Find Specialized Care for Your Child

Regardless of the cause of your child's PH, this disease is complex, and can be difficult to understand and treat. It is essential to find a specialized pediatric PH care team – doctor, nurse, social worker, child life specialist, etc. – comprised of experts who can advise you about your child's options for treatment and care.

Because PH is a complex disease, PHA encourages you to locate specialists with expertise in this disease. To that end, PHA provides a directory of pediatric PH specialists and accredited PH Care Centers (PHCCs) on its website.

PH Care Centers	www.PHAssociation.org/PHCareCenters/Peds
Find a Doctor	www.PHAssociation.org/Patients/DoctorsWhoTreatPH (search for "pediatrics")

If PHA's directories do not list pediatric PH specialists close to your home, try asking your child's current medical team for a referral, contacting your personal networks for recommendations or searching for pediatric medical facilities online.



PHA encourages you to ask about palliative care, a multidisciplinary medical specialty that focuses on whole-person care for seriously or chronically ill individuals and their caregivers. Palliative care prioritizes symptom and pain relief, care coordination and patient and family goals.

Connect with Other Families

Many other families are also experiencing, or have experienced in the past, what you are working through now. They understand how isolating, confusing and frightening this situation is for your child, your family and you. But you are not alone, and there are other families who are connected with PHA who may have information and tips that can help you. Consider using PHA's resources:

Select an email mentor through **PHA's mentor program** to ask another parent of a child with PH questions or to ask for support at www.PHAssociation.org/mentors/caregivers.

Join **myPHA**, an online forum for people with PH and their families to ask questions, share stories and offer peer-to-peer advice. Sign in and post at www.PHAssociation.org/myPHA.

Many **PHA support groups** include families with children; some are even pediatric specific. Contact the leader of the group nearest you for information. If there is not a PHA support group in your area, PHA can help you start your own. To learn more, visit www.PHAssociation.org/localsupportgroups.

PHA hosts a **quarterly support call just for parents**. Register for the next call at www.PHAssociation.org/parents/support.

PHA's International PH Conference is the world's largest gathering of PH patients, families and health care professionals. We offer special programs during our conference just for children and parents. PHA also offers scholarships to help cover the costs to attend. Learn more at www.PHAssociation.org/Conference.

Connect with PHA on social media:

 www.Facebook.com/PulmonaryHypertensionAssociation

 www.Twitter.com/PHAssociation

 www.Instagram.com/PHAssociation

Find the Emotional Support Your Family Needs

A PH diagnosis for your child can take an emotional and psychological toll on all members of the family. In addition to connecting with others, seek professional mental health help for yourself, your child or other family members. Your PH care team may be able to provide you with a referral to mental health support services (often called "behavioral health").



To view our print resources, including *Pulmonary Hypertension: A Patient's Survival Guide* and PHA's free *Living with PH: A Guide for Parents*, visit www.PHAssociation.org/PHA-Pediatrics.

Teenagers

If your child with PH is between the ages of 13 and 19, PHA provides unique resources just for them at www.PHAssociation.org/Patients/Living-With-PH/Teens, including:

- A PHA staff-moderated Facebook group for teens
- *Living With PH: A Guide for Teens*
- Connecting with a young adult mentor

Work with Your Child's School

Frequent doctor's visits, symptoms, side effects or the mental and emotional effects of life with PH give parents of a child with PH the right to request resources, assistance or accommodations from their child's school. There are several steps you can take to manage your child's school experience:



Talk to school administrators and your child's teachers. Explain the situation and tell them specifically what you need and expect from them, and what they can expect from you. Create a clear exercise or excusal plan with the physical education teacher with guidance from your child's pediatric PH specialist.



Meet with your child's school administrators to discuss federal laws and programs designed to help your child succeed in school. These include 504 plans, and Individualized Education Programs (IEPs), which spell out the accommodations your child needs to participate successfully in school. Learn more about 504 plans and IEPs at www.PHAssociation.org/Parents/Planning-For-School/Plans-For-PH-Parents.



Communicate with the school and local emergency departments about your child as soon as he or she is diagnosed, and again each year before the school year begins. Provide a detailed instruction sheet about emergency procedures so that if the school calls 911 for your child, the emergency medical services team takes the correct steps and precautions (for example, if your child is on infusion therapy, ensure that your instruction sheet includes directions not to flush the line or stop medication at any time).



Work with the school and your child's specialty pharmacy, child life team, social workers and/or PH care team to conduct training at the school to educate teachers, staff and students about PH and your child's needs. Remember to include the school nurse, who can be a valuable resource and advocate for your child.



Families who home-school their children may benefit from some of the above resources and may also network through national, state or local networks of home-schooling families and resource providers.

For more information about school and to download a handbook, visit www.PHAssociation.org/Parents/Planning-For-School.

The Pulmonary Hypertension Association

The Pulmonary Hypertension Association (PHA) is the world's largest, oldest PH patient advocacy organization. PHA offers resources and services to anyone affected by PH – including families and children. We welcome you to learn more about the organization and get involved at www.PHAssociation.org.

PHA is grateful for the sponsorship support provided by
Actelion Pharmaceuticals U.S., Inc.

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