

A quick reference guide for school staff and other adults in your loved one's life



About PK deficiency

Pyruvate kinase (PK) deficiency is a hereditary chronic hemolytic anemia. This means that:

- People with PK deficiency are born with it and will have it throughout their lives
- It's a form of anemia caused by a problem with red blood cells

Red blood cells (RBCs) carry oxygen to every part of the human body. To create the energy to do their job, they need the PK enzyme. Without enough PK, RBCs can't make enough energy and

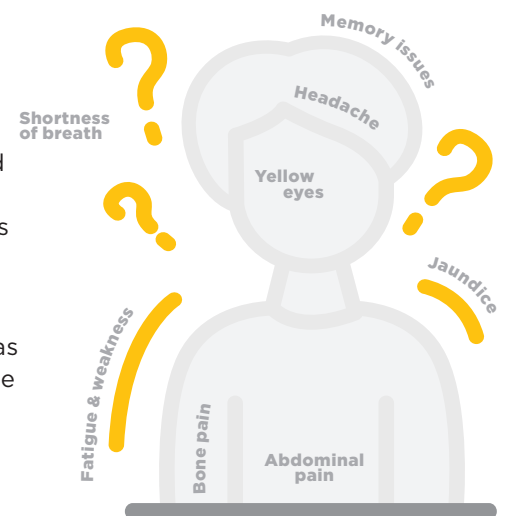
- Can't carry as much oxygen
- Don't live as long as they should, which means that the body has fewer healthy RBCs
- Break down and release ferritin (iron) and bilirubin into the bloodstream, which can cause other health problems

That can lead to a wide variety of symptoms and complications, some serious in nature.

PK deficiency symptoms

Fatigue is a common symptom of PK deficiency, and it can vary from mild to very severe. While this fatigue may not always interfere with everyday life, there are times when this fatigue can be debilitating, making activities difficult, including physical activities like school sports or gym class.

Another symptom of anemia is "brain fog," which can interfere with memory or the ability to think clearly. But PK deficiency symptoms such as fatigue can vary greatly from day to day, and even among different people who have the same disorder.



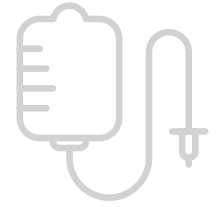
About jaundice

A visible symptom of PK deficiency is jaundice, which is caused by RBCs breaking down too quickly for the liver to manage. High levels of bilirubin are released into the bloodstream, causing the skin and/or eyes to turn yellow.

When people with PK deficiency have jaundice, they often receive unwanted attention: looks, comments, accusations of substance abuse, and bullying. To minimize negative attention, it may be helpful to let classmates, teammates, and friends know that jaundice is a symptom of PK deficiency and that it's not contagious. Note that, because jaundice is the result of RBCs breaking down, other symptoms may be present as well.

About transfusions

There is no cure for PK deficiency. Doctors, nurses, and other healthcare providers work with people with PK deficiency to manage the symptoms of the disease. One way to manage symptoms is through the transfusion of red blood cells. Some people with PK deficiency may need transfusions on a regular basis. Others may need them only if they have an infection or because certain symptoms have worsened.



Because transfusions can take up to 4 hours to administer, not including time needed for observation or travel, the need for a transfusion may mean missing school, sometimes on a regular basis. Proactively plan for absences in terms of make-up work, and communicate plans to the child and their caregiver. This can help minimize disruption to schoolwork and other activities.



Please notify our family in the case of schoolwide illness

People with PK deficiency may be more prone to illness, so if there is an outbreak of the flu; chicken pox; hand, foot, and mouth disease; or other illness, please let us know. Many people with PK deficiency have had their spleen removed (splenectomy), which also decreases the body's ability to fight infection. People with PK deficiency may also take longer to recover from an illness than is typical.

PK deficiency and everyday life

My child typically has the following symptoms:

The symptoms of PK deficiency can

- affect concentration
- mean that more time is needed to problem-solve or complete tasks
- limit participation in certain activities, active games, or sports
- increase the need for rest after exertion

My child may need accommodation, specifically with regard to

My child may need to be absent on a regular basis for doctor visits (describe frequency or add known dates)

My child may need to be absent on a regular basis for transfusions (describe frequency or add known dates)

My child will need to visit the school nurse to take medication on a daily basis (describe medications and dosage)

Please contact me in the event of the following, and notify emergency medical services as appropriate:

- Abdominal pain accompanied by nausea and/or vomiting
- Chest pain
- Fever
- Loss of consciousness
- Shortness of breath that does not resolve with rest

Other (please describe)

Contact information

Parent/caregiver name

Alternate contact

Phone number

Relationship

Please reach out by

Calling Texting

Phone number

Please reach out by

Calling Texting

Doctor's name

Phone number

Medical information for EMTs:

If emergency medical services needs to be called, please notify me, my child's doctor, and share the following:

Name

Other major surgery

Date of birth

Diagnosed with PK deficiency

Spleen removed (splenectomy)

Gallbladder removed (cholecystectomy)

Average hemoglobin

Treating physician



To learn more about PK deficiency, visit [KnowPKDeficiency.com](https://www.knowpkdeficiency.com).

Except in the case of a medical emergency, this information should only be shared with those directly involved with the student's education or activities (eg, teachers, coaches, school nurse); supplying medical care; or are otherwise acting *in loco parentis*.