



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.™

Helping Hand™

Health Education for Patients and Families

Pseudotumor Cerebri (PTC)

Pseudotumor cerebri (SOO-doe-too-mur SER-ree-bry) (PTC) is also known as idiopathic intracranial hypertension (IIH). It is a disease that causes increased pressure in the brain. It occurs in about 1 out of every 100,000 children. Most of the time there is no obvious cause for the increased pressure. If a cause is found it is referred to as secondary intracranial hypertension. This can be a direct result of specific medicine use or a known condition. The increased intracranial pressure can put pressure on the optic nerve which can cause vision loss. If treated early, vision loss can be prevented. If it is not treated quickly, permanent vision loss and chronic pain due to headaches may occur. The term pseudotumor is used because the condition mimics brain tumor symptoms that occur when excess fluid adds pressure to the brain.

Risk factors

Common risk factors for developing PTC/IIH are:

- obesity
- use of high-risk medicines (includes those that come from Vitamin A, like Accutane®, tetracycline medicines, such as minocycline, and steroids)
- post-puberty
- female

Signs and symptoms

The most common signs and symptoms are:

- headache
- double vision
- eyes that turn inward (esotropia)
- nausea and vomiting
- blurry vision
- ringing in the ears (tinnitus)

- swelling of the optic nerve (papilledema)
- transient obscuration of vision (TOV) – Your child’s vision is hazy or unclear. This can come and go.

Diagnosis

Your child will have a complete eye exam that lets their health care provider look at the optic nerve. The exam includes:

- visual acuity - being able to read letters or match pictures at a set distance
- color vision testing - being able to see color
- pupil and motility testing - how eyes align in different positions
- fundus photography (photos of the inside of the eye) and a special image of the optic nerve called an OCT
- visual field testing

Your child may also have the following tests to confirm their diagnosis:

- brain magnetic resonance imaging (MRI) or computerized tomography (CT) scan
- lumbar puncture

It is important to note that surgery is rarely needed. If it is, it may include procedures called optic nerve sheath fenestration and cerebrospinal fluid shunting. You will get more information on these if your child needs surgery.

Treatment

The most common ways to treat PTC are weight loss if needed, and acetazolamide (Diamox®) or furosemide. These are water pills (diuretics) that help the body lose fluid.

Follow-up

In 2 out of 3 children, when the PTC goes away, they will get consistent headaches. These headaches can differ from the headaches they got when diagnosed with PTC. This is one reason it is important to keep follow-up appointments with their health care provider and the neurology team.

Be sure to write down all of your questions as you think of them. Bring this list with you when you see the health care provider. Call your health care provider if you cannot keep an appointment.