



[This page prints out on 4 sheets]

## **Usher Syndrome**

**Read this page if your child has a hearing loss and also has a vision or seeing problem. That could mean he has Usher Syndrome.**

### **What is Usher Syndrome?**

**Usher Syndrome (UH-shur SIN-drum)** is a disease that makes people lose some of their hearing and some of their vision. The vision loss is caused by a disease called **Retinitis Pigmentosa**. Doctors call this disease **RP** for short.

**People with Usher Syndrome are usually born with some hearing loss.**

The amount of hearing loss is different for different people:

- It can be mild, moderate, severe, or profound.
- It can get worse over time. This is called **progressive hearing loss**. Or the hearing loss can stay the same.

**People with Usher Syndrome usually lose their sight later in life.**

People with Usher Syndrome lose their night vision first. That means they have trouble seeing in the dark.

It usually starts to happen when the person is a teenager. But it can also happen earlier, during childhood.

### Not everyone loses the same amount of seeing and hearing

People with Usher Syndrome usually don't lose all of their hearing and sight. But they usually have lost a lot of their sight by the age of 30 or 40. This kind of sight loss is called being **legally blind**.

Being legally blind doesn't mean a person can't see anything. It means they can only see what is right in front of them, and close to their eyes. They can't see things on the side, or things that are far away. They might be able to read regular books. Or they might need to learn Braille.

### **What causes Usher Syndrome?**

Usher Syndrome is a genetic disease. That means you're born with it.

To be born with Usher Syndrome, a child must get the gene for Usher Syndrome from both parents. This does not mean that both parents have to have Usher Syndrome. If neither parent has Usher Syndrome, but both parents are carriers of the gene, when the two carriers combine, their child might be born with Usher Syndrome. Both girls and boys can have Usher Syndrome.

### **Signs of Usher syndrome**

Even if your child is born with Usher Syndrome, you may not know it right away. Why? Because your child may be born with a hearing loss. But he may not lose his sight until later.

But special testing can be done to check your child's eyes. This will let them know before the child has a vision problem.

These things may mean your child is losing his sight:

- trouble seeing things in the dark or in dim light
- a lot of accidents, like bike accidents or bumping into people
- getting worse at understanding sign language (if your child uses sign language)
- sitting very close to the TV (many parents think this is because he is deaf!)
- holding things very close to see them
- trouble balancing, like not being able to walk across a balance beam at the playground

### **If you think your child has Usher Syndrome**

If you think your child has Usher Syndrome, get your child tested for it. There's no cure for Usher Syndrome. But knowing if your child has it can help you plan for the future better.

- They can figure out when and how to teach the child special things (like Braille) so that he can still succeed when he starts to lose his vision.
- Some parents choose to teach their child sign language, because speech reading will not be easy if seeing is hard.
- Other parents may choose a [cochlear implant](http://www.raisingdeafkids.org/help/tech/ci/) (<http://www.raisingdeafkids.org/help/tech/ci/>), because they want to make hearing things as good as possible.

So if your child has some of these signs, don't wait:

- Tell your child's doctor right away.
- Don't let your doctor tell you not to worry. You have a right to know.
- Take your child to an eye doctor. The doctor is called an **ophthalmologist (opp-thah-MOL-o-jist)**. The ophthalmologist will do a test called an **electroretinogram** to find out if your child has Usher Syndrome. Ask the ophthalmologist if your child should see another kind of doctor, called a retina specialist.

### **How you can help your child**

It's hard knowing that your child may face hardships in her life. Maybe you felt upset or depressed when you first found out. That's normal. But you are not alone. And there are many things you can do to help your child.

### **Telling your child he has Usher Syndrome**

One of the hardest things for parents to do is to tell their child that he will lose some of his vision. Some parents feel like they have to do this right away.

But you can wait. If your child is very young, he might not understand anyway. For now, just tell him just enough to keep him safe:

- Tell him that he might have more trouble than other kids seeing things at night. Tell him to be extra-careful when he crosses the street or rides his bike.
- Or tell him to ask mommy or daddy to hold his hand if he's ever afraid of falling down.

### **Helping your child in school**

A lot of people with Usher Syndrome do very well in school. With the right help, they can graduate from high school, college, graduate school, and get very good jobs. But your child will need extra help:

- Get your child help through an [Early Intervention](http://www.raisingdeafkids.org/learning/ei/) (<http://www.raisingdeafkids.org/learning/ei/>) program.
- Make sure his [IEP](http://www.raisingdeafkids.org/help/rights/school/idea/iep.jsp) (<http://www.raisingdeafkids.org/help/rights/school/idea/iep.jsp>) says that he has Usher Syndrome.
- Tell your child's teachers that your child has Usher Syndrome. Explain what it is to them. They may never have heard of it.
- Give your child's teachers names of websites, articles and books about Usher Syndrome. That way they can learn more on their own. Show them this page, and the list of links at the bottom of the page.

### **Helping your child deal with Usher Syndrome**

Maybe your child is upset about losing her sight. Many children with Usher Syndrome feel that way. It's especially hard for these children when they're teenagers. But you can help. Here's how:

- Help your child talk about his feelings. Sometimes children see that their parents are upset and feel bad. A child might think that it is his fault his parents are sad. Tell your child it is not his fault. He didn't do anything wrong.
- If your child is depressed for a while, have her talk to a psychologist or a psychiatrist. These are people that know a lot about how children and teens cope with medical problems. They can help him with his feelings.
- Help your child meet other children with Usher syndrome. Meeting these children will help your child know that she's not alone. Help her stay in touch with these children through e-mails, letters and visits.

Read our section on [depression](http://www.raisingdeafkids.org/special/depression/) (<http://www.raisingdeafkids.org/special/depression/>) to find out more ways to help your child if he is sad or angry.

### **Find out what kind of Usher Syndrome your child has**

Knowing what kind of Usher Syndrome your child has can help you know what to expect. So get her tested.

There are 3 kinds of Usher Syndrome.

- Each kind is caused by different genes.
- The 3 kinds affect people differently.
  - For example, 1 kind usually makes people lose more vision than the other kinds.

To find out what kind your child has, a doctor can do [genetic tests](#) (<http://www.raisingdeafkids.org/hearingloss/genetics/counseling.jsp>) on your child.

### **Get your other children tested**

Usher Syndrome runs in the family. So get your other children tested for it. But try not to worry - there's only a very small chance that they have it, too. (Chances are higher when the other children also have a hearing loss.)

### **Learn more about Usher Syndrome**

- Read [one mother's story](#) (<http://www.raisingdeafkids.org/meet/parents/deafplus.jsp#usher>) about finding out her child had Usher Syndrome.
- Check out the [National Family Association for the Deaf-Blind's website](#) (<http://www.nfadb.org/Information.html>) to find out who can help you in your state.
- Read the National Information Clearinghouse on Children who are Deaf-Blind's [pages on Usher Syndrome](#) (<http://www.tr.wou.edu/dblink/usher-intro.htm>).
- Read the Deafblind Association's [information on Usher Syndrome](#) (<http://www.dba.asn.au/usherinf.htm>).
- Read one man's story about [growing up with Usher Syndrome](#) ([http://www.boystownhospital.org/parents/info/genetics/my\\_life.asp](http://www.boystownhospital.org/parents/info/genetics/my_life.asp)).
- Check out Foundation Fighting Blindness's [message board](#) (<http://www.blindness.org/msgboard/msgboard.asp>) on Usher Syndrome (go to this page and click on Usher's Syndrome).
- [Helen Keller Services for the Blind](#) (<http://www.helenkeller.org>) has a lot of information about services and programs for children and adults who are deaf and blind.
- Located in Philadelphia, [Overbrook School for the Blind](#) (<http://www.obs.org>) offers a variety of programs for children of different ages and abilities. The whole school is geared toward supporting students as they grow and learn.

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You can find this page online at:

<http://www.raisingdeafkids.org/special/usher/>