Congenital Cataract

Patient Information Series – What you should know, what you should ask.

What is congenital cataract?

Congenital cataract refers to clouding of the lens of one or both eyes, which is present at birth. Normally, the lenses of the eyes are crystal clear. Some forms of cataract are minor (small dots in the lens) and do not progress. These minor forms do not interfere with vision. However, other forms present with total clouding of the lens or start small and progress over time. These forms can produce serious vision problems.

How does congenital cataract happen?

Congenital cataract can occur for many reasons. It is known that when there is a family history of congenital cataract, the risk of having a baby with congenital cataract is higher. Sometimes, cataract is part of a syndrome such as Down syndrome. People with Down syndrome have an extra chromosome number 21. The chromosomes are packages of genetic information. Changes in the number of packages or in the information itself can cause genetic diseases. Congenital cataracts have been noted in many genetic diseases that are causes by such changes.

More rarely, congenital cataract is the result of metabolic problems (a change in how our body processes things), diabetes or the intake of certain medications like coumadin derivates (blood thinning pills) by the pregnant mother. There is also a risk that congenital cataracts occurs when the mother suffers from infections such as measles or rubella during pregnancy. Despite all these previously mentioned causes which can lead to congenital cataract, it frequently happens that no reason is found why a baby has cataract at birth

Should I have more tests done?

You should ask if a specialized/advanced ultrasound of the baby during the pregnancy can be performed to see if the baby has other anomalies or if the cataracts are the only issue. If there are other anomalies, a consultation with a genetic specialist is usually recommended. You may be offered testing by amniocentesis to see if certain genetic changes are the cause for the cataract. Amniocentesis is done using a thin needle that is inserted in your belly to collect some of the water in the sac around the baby. There is a small risk of miscarriage (less than 1 miscarriage for every 200 amniocentesis done) and some women choose not to have it performed out of fear for losing their baby. Not all conditions can be diagnosed by amniocentesis, and not all anomalies can be seen on ultrasound. However, if there are no other anomalies seen on ultrasound and invasive testing gives normal results, then cataract is likely to be isolated.

What are the things to watch for during the pregnancy?

If there are no other anomalies, then you can have your pregnancy checks as normally planned. If there are other anomalies, changes in your care will depend on what they are and what they mean.

What does it mean for my baby after it is born?

If the cataract is severe, the baby will not see well through the affected eye. This makes it hard for the brain and eyes of the baby to work together. If the brain does not get clear images of the world from the eye because of the cataract, then the brain does not learn how to interpret the images it receives.

If the lens is not replaced by surgery, vision through the affected eye is not corrected and the brain supresses the poorer-quality image of that eye and works mostly with the clearer image. This can lead to problems like blindness, amblyopia (also called “lazy eye”), nystagmus (rapid and uncontrollable movement of the eyes), strabismus (the eyes are not aligned properly and point in different directions) or the inability to fix a gaze upon objects.

Now that surgeries can be done within the first few months of life, the visual outcome and quality of life is usually good. The vision of the operated eye will have to be corrected with an artificial lens placed in the eye, contact lens or eyeglasses. Long-term follow-up and frequent monitoring of the eye by an eye specialist is usually recommended.

How well the baby sees may not be as good if there are other eye anomalies like a small eye (called microphtalmia). The baby may have more problems after birth when the cataract is part of a genetic condition, a syndrome or when there are other anomalies. How well the baby is will depends on those other issues.

Will it happen again?

When the cataract is on one side only, there is no family history and there are no other anomalies, the risk of having another child with cataract is small. However, it is difficult to estimate the exact risk and consultation with a genetic specialist may be helpful in sorting this out.

If cataract is part of a genetic condition or syndrome, then the risk that it will happen again depends on that specific condition. In this situation, consultation with a genetic specialist is strongly recommended. If the cataract was caused by an infection, it is very unlikely to happen again.

What other questions should I ask?

- Does it affect one or both eyes?
- Does this look like a severe form of cataract?
- Are there other anomalies visible?
- Are there other tests like an amniocentesis recommended?
- How often will I have ultrasound examinations done?
- Where should I deliver?
- Where will the baby receive the best care after it is born?
- Can I meet in advance the team of doctors that will be looking after my baby when it is born?

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