CONDITION

Expanded rubella syndrome

Expanded rubella syndrome is a broad pattern of birth differences caused by rubella infection during pregnancy.

WHAT IT IS
Congenital rubella affecting several organs

BODY SYSTEM
Hearing, eyes, heart, brain, blood, and growth

MAIN SYMPTOMS
Hearing loss, eye problems, heart defects, developmental delay

WHAT CAUSES IT
Rubella infection during pregnancy

HOW IT IS DIAGNOSED
Infant rubella antibody tests and viral PCR

MAIN TREATMENT
Supportive care, rehabilitation, and corrective procedures

CAN IT BE CURED?
No - established birth changes are permanent

IS IT AN EMERGENCY?
Sometimes - breathing difficulty or a seizure

LONG-TERM OUTLOOK
Ranges from mild disability to serious lifelong health problems

Overview

Expanded rubella syndrome is a broad form of congenital rubella syndrome. "Congenital" means present from birth. It develops when rubella virus passes from a pregnant person to the developing baby.

Rubella usually causes a mild rash illness in children and adults. During pregnancy, however, it can interfere with organ development, especially when infection occurs early.

The classic form of congenital rubella syndrome involves hearing loss, cataracts and heart defects. "Expanded" describes a wider range of effects involving the brain, liver, blood, bones, lungs, growth or hormone-producing organs.

Some children have one main problem, while others have several medical and developmental

needs. Certain effects are present at birth, but hearing, learning, vision or hormone problems may become apparent later.

Expanded rubella syndrome is not inherited and is different from catching rubella after birth. Vaccination has made it uncommon in places with strong vaccination programs, but cases can occur when a pregnant person without immunity is exposed.

Symptoms

Possible findings at birth include:

Hearing loss is one of the most common lasting effects. It may affect one or both ears and range from mild to profound. Because it may not be obvious in a newborn, formal hearing tests and follow-up are important.

Eye problems can include cataracts, damage to the light-sensitive layer at the back of the eye, or raised pressure inside the eye.

Heart findings may include a persistent connection between major blood vessels or narrowing of an artery leading to the lungs. A significant defect may cause rapid breathing, tiring during feeds, slow weight gain or a blue-grey colour around the lips.

Brain and developmental effects can include delayed movement or speech, learning disability, reduced muscle tone, seizures, or difficulties with coordination and behaviour. Severely affected newborns may have inflammation of the brain and surrounding tissues.

Some children later develop thyroid or blood sugar regulation problems.

- Low birth weight or slow growth before birth
- A purple-red spotted rash caused by bleeding under the skin
- Jaundice
- An enlarged liver or spleen
- A small head size
- Cataracts
- Heart defects affecting blood flow
- Poor feeding, unusual sleepiness or breathing problems

Causes and risk factors

Expanded rubella syndrome is caused by rubella virus crossing the placenta during pregnancy. The risk of fetal infection and serious developmental effects is greatest early in pregnancy, when organs are forming. Later infection is less likely to cause the full syndrome, although hearing loss and other effects can still occur.

The main risk factor is being pregnant without rubella immunity and being exposed to the virus. A person may lack immunity because they were not vaccinated, did not complete the recommended schedule, or lived where vaccination was not widely available.

Travel or contact with people from areas where rubella circulates can increase exposure risk. Rubella can be difficult to recognize because its rash and fever resemble other infections, and some people have few or no symptoms.

The condition is not caused by anything a pregnant person ate, did or failed to notice. It is not passed down through families.

Diagnosis

Diagnosis is based on the child's findings and tests showing congenital rubella infection. Physical features alone cannot confirm it because other infections and genetic conditions can cause similar problems.

Blood tests may detect rubella-specific IgM antibodies produced by the baby. Tests may also show IgG antibodies that remain longer than antibodies transferred from the pregnant parent would be expected to last.

Reverse-transcription polymerase chain reaction, or RT-PCR, can detect viral genetic material. Samples may come from the throat, nose, urine or other body fluids. Testing requires specialist and public health interpretation.

Tests to assess affected organs may include:

Tests during pregnancy can help establish whether the pregnant person recently had rubella, but a positive result cannot show how severely a fetus is affected. Rubella IgM results can sometimes be misleading, so specialist laboratory confirmation may be needed.

- Formal hearing assessments
- A complete eye examination
- Heart ultrasound and electrical heart testing
- Blood counts and liver tests
- Brain imaging when medically indicated

- Growth and developmental assessments

Treatment and management

No treatment removes congenital rubella virus or reverses structural changes that developed before birth. Care treats specific problems, supports development and aims to identify later effects early.

The care team may include hearing, vision, heart, developmental and infectious disease specialists. Treatment may involve hearing aids, cochlear implants, communication support, and early speech and language services, including sign language when appropriate.

Cataracts that significantly affect sight may require surgery. Glasses, treatment for raised eye pressure and low-vision support may also be needed.

Some heart defects can be monitored. Others require medicines, a catheter procedure or surgery. Feeding and nutrition support may help children whose heart or neurological problems make feeding difficult.

Physiotherapy, occupational therapy and educational support can improve movement, communication, independence and participation.

Regular follow-up may include hearing and vision checks, growth measurements, developmental reviews and selected blood tests. Monitoring should continue even when a child seems well because some hearing, eye or hormone problems appear later.

Babies with congenital rubella can release virus in urine and respiratory secretions for many months. The care team and public health service may recommend testing and infection-control precautions, especially around pregnant people without confirmed immunity.

Complications

Possible long-term complications include permanent hearing loss, reduced vision, heart strain, learning disability, and difficulty with movement or communication. The effects depend on which organs were injured before birth.

Poor feeding, heart disease or liver problems can affect growth. Cataracts may disrupt early visual development if not treated promptly. Unrecognized hearing loss can affect spoken-language development.

Less common complications include thyroid disorders, diabetes and a rare progressive inflammation of the brain that may appear years later. These do not affect every child, but

planned long-term follow-up can identify treatable changes early.

Prevention

Expanded rubella syndrome can usually be prevented by preventing rubella infection during pregnancy. It cannot be prevented after fetal infection and developmental injury have occurred.

The measles, mumps and rubella vaccine, or MMR, protects against rubella. Because it is a live vaccine, it is not routinely given during pregnancy. Immunity can be checked before pregnancy and vaccination given if needed. The US Centers for Disease Control and Prevention advises avoiding pregnancy for 28 days after MMR vaccination.

People found to be non-immune during pregnancy are generally offered vaccination after the pregnancy, often soon after birth, to protect future pregnancies. MMR vaccination given by mistake during pregnancy is not, by itself, considered a reason to end the pregnancy.

If you are pregnant and may have been exposed to rubella, contact your maternity care team promptly. Do not wait for a rash. They can review your vaccination history, arrange appropriately timed blood tests and involve infection specialists.

Routine childhood vaccination reduces community spread and helps protect pregnant people who cannot receive MMR at that time.

Living with it and what to expect

The outlook depends on which organs are involved and how severely they were affected. Structural changes such as major hearing damage or certain eye and heart defects do not disappear, but procedures, devices and rehabilitation may reduce their effects.

The first months may involve frequent appointments for feeding, heart, eye or infection-control needs. Later, care often focuses on communication, mobility, education and participation in family life.

Development may follow a different timetable, but progress can continue throughout childhood. Early communication and developmental support can help a child build skills.

Some children attend mainstream school with hearing, vision or learning support. Others need more extensive help with education and daily activities. Adults may continue to need hearing care, eye checks, heart follow-up or disability support.

New problems should not automatically be attributed to the syndrome. Routine healthcare,

dental care, vaccinations and assessment of new symptoms remain important.

When to get medical help

Arrange routine medical review if a child has:

Seek urgent medical care for rapid breathing, worsening feeding, unusual drowsiness, a new widespread purple rash, or signs that a heart condition is becoming harder to manage.

Call emergency services for severe breathing difficulty, blue-grey lips or skin, a seizure lasting several minutes, repeated seizures without recovery, collapse, or difficulty waking the child.

If you are pregnant and have had close contact with someone who may have rubella, contact your maternity service or public health team promptly. Timely assessment is needed, but emergency services are not usually necessary unless you are otherwise seriously unwell.

- Reduced response to sound or a change in hearing
- New difficulty seeing, eye pain or an unusual white pupil
- Slow weight gain, feeding difficulty or reduced stamina
- Loss of a skill they previously had
- Changes in thirst, urination, growth or energy that could indicate a hormone problem

Common questions

Is expanded rubella syndrome the same as congenital rubella syndrome?

It is usually considered a broad or severe pattern within congenital rubella syndrome rather than a separate condition. The term emphasizes that organs beyond the classic hearing, eye and heart findings may be involved.

Can a baby look healthy at birth and still have it?

Yes. Hearing loss or milder developmental and eye problems may not be obvious at birth. Laboratory evidence and planned follow-up can identify effects that appear later.

Can expanded rubella syndrome be cured?

No treatment reverses all prenatal injury. Individual problems may still be treated with heart procedures, cataract surgery, hearing technology, communication support and developmental therapies.

Can I catch rubella from a child with congenital rubella?

An affected baby can release rubella virus in respiratory secretions and urine for months. Public health teams may recommend precautions and testing, especially around pregnant people without confirmed immunity.

Does having rubella in pregnancy always affect the baby?

No. Risk and severity depend strongly on when infection occurs, with the greatest risk early in pregnancy. A rash or single test cannot predict an individual baby's outcome, so specialist assessment is needed.

Will another baby have the same condition?

Expanded rubella syndrome is not inherited. A future pregnancy is not expected to be affected if the pregnant person has reliable immunity and does not acquire rubella. Vaccination records or immunity testing can be reviewed before pregnancy.

Sources

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