

## Factsheet – 19

# THE DELAYED EFFECTS OF CONGENITAL RUBELLA SYNDROME

## What is Congenital Rubella Syndrome?

Rubella, also known as German measles, was once a common disease of childhood. It is caused by a virus which is spread in the air as droplets – through close contact and by coughing and sneezing.

Rubella infection in childhood usually presents no serious complications, but if caught by a woman in the early stages of pregnancy may cause miscarriage, stillbirth or serious health problems for the affected foetus. The term 'Congenital Rubella Syndrome' is used to describe the range of health problems that may be present at or around the time of birth. The effects of Congenital Rubella vary depending on what stage of pregnancy the infection was contracted and how invasive it has been.

Worldwide rubella epidemics from the 1940's to the 1960's resulted in many babies being born with Congenital Rubella Syndrome. Those babies are now adults and even though rubella epidemics are now less common, the ongoing effects of congenital rubella remain. In fact, many individuals with Congenital Rubella may go on to develop additional problems to the ones they were born with.

This factsheet aims to provide affected individuals, their families, carers and other involved professionals with an overview of the early, ongoing and delayed effects of Congenital Rubella. Knowing what may develop can help in earlier diagnosis and the implementation of appropriate medical treatment and management programmes where necessary.

## Common early problems

Many organs that develop in the early stages of pregnancy can be affected by rubella infection. Some of the common effects of rubella during pregnancy include impairments to ears, eyes, heart, brain and nervous system:

- Many children have sensorineural hearing loss in one or both **ears**. This is because the inner ear, which links the ear to the brain, has been damaged. A child's hearing may also get worse over time.
- Babies may be born with cataracts (cloudy lenses) in one or both **eyes**. Others may have rarer visual conditions or find that their sight gets worse as they get older.

- Rubella can affect the **heart** in many different ways. Children may have heart problems from birth and require hospital treatment.
- Rubella can also affect a child's **brain** and **nervous system**. Difficulties can vary from mild to severe.

The above, are only brief descriptions of what can happen as a result of rubella, and it is important to remember that no two individuals will experience the effects of Congenital Rubella in exactly the same way. Most people will have one effect (usually hearing loss) as well as some combination of the other effects mentioned in this factsheet.

A paediatrician can help explain how a child has been affected.

### **Delayed effects associated with congenital rubella syndrome**

We do not know for certain how the rubella virus continues to affect an individual with Congenital Rubella Syndrome. Most experts believe that new problems are either due to a persistent infection of the rubella virus in the affected organ, or to the old infection which sets up an auto-immune response (i.e. the body's immune system reacts against its own tissue in the mistaken belief that it is the rubella virus).

Most people are able to identify changes in their own health and seek advice and treatment. However, many people with congenital rubella are not able to communicate underlying symptoms. It is therefore important to regularly monitor an individual's well-being. Monitoring should include regular medical assessment.

The increased incidence of the following conditions has been confirmed by research<sup>1</sup>. This means that these conditions occur more frequently amongst people with congenital rubella than they do in the general population. However, no two individuals are affected by congenital rubella in the same way.

- **Diabetes Mellitus**

Diabetes occurs when there is a high level of glucose in the blood (hyperglycaemia). This occurs when the pancreas does not produce enough insulin or the body is unable to utilise the insulin produced.

**Signs and symptoms to look out for include:**

- increased thirst
- going to the toilet all the time – especially at night
- extreme tiredness
- weight loss
- genital itching or regular episodes of thrush
- blurred vision.

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<sup>1</sup> Logan, S and Tookey, PA. (3<sup>rd</sup> ed.) (1996) *Rubella Infection*; in **Oxford Textbook of Medicine** Weatherall, D., Ledingham, JGG and Warnell, DA. (eds.). Oxford University Press, New York 1996. pp 409 – 412 (and Concise Oxford Textbook of Medicine).

If you, or someone you know, experiences any of these symptoms, seek advice from your GP who may do a blood test to check your glucose levels. Although there is no cure, careful monitoring and treatment means diabetes can be managed very successfully.

- **Thyroid dysfunction**

The thyroid is a small gland situated in the neck. Its function is associated with the body's use and turnover of energy. The thyroid can be underactive (hypothyroidism) or overactive (hyperthyroidism).

**Signs and symptoms to look out for include:**

**Hypothyroidism**

- Mental and physical slowness
- Weight gain
- Cold intolerance
- Constipation
- Dry skin
- Lethargy
- Memory loss
- Heavy periods
- Hoarse voice
- Swollen eyes
- 'Dull' hair

**Hyperthyroidism**

- Fast pulse
- Hand Tremor
- Weight loss
- Heat intolerance
- Diarrhoea
- Excessive sweating
- Decreased need for sleep
- Anxiety and becoming increasingly emotional
- Protrusion of the eyes

If any of the above symptoms are being experienced, these should be discussed with the individual's GP. The GP may ask some questions and decide to do a blood test. Thyroid dysfunction can be detected by measuring levels of hormone in the blood. Again, there is no cure but careful monitoring and treatment means thyroid disorders can be managed very successfully.

- **Glaucoma**

Glaucoma is an abnormal increase of pressure within the eye (intraocular pressure - IOP) which may result in optic nerve injury and affect the vision. As pressure in the eye builds up, there is a progression from mild visual impairment, and if left unchecked can lead to blindness. Glaucoma can develop later in life as a result of cataract surgery.

**Signs and symptoms to look out for include:**

- Loss of peripheral vision
- Pain in the eye
- Redness of the eye
- Increased rubbing of the eye
- Misty rainbow coloured rings can be seen around white lights

An optometrist can perform several tests to check for glaucoma. If glaucoma is identified, it can usually be managed with the daily use of eye drops.

## **Other delayed manifestations that have been reported by affected individuals, families and professionals**

Other possible delayed effects described below have been reported by affected individuals, families and other professionals from around the world<sup>23</sup>. However, there is no scientific evidence to indicate that individuals with congenital rubella are at an increased risk of developing these conditions.

### **• Declining Hearing Loss**

Hearing loss may range from mild to severe and is the single commonest effect of Congenital Rubella. For most people it remains stable but for others it may be progressive.

A person with declining hearing loss may experience new problems, which can include:

- Having to turn the television volume up louder
- Difficulty maintaining a telephone conversation
- Difficulty hearing some high frequency sounds
- Difficulty identifying the direction that sounds are coming from

For example, wax in the ears can reduce an individual's ability to hear, and even though not progressive, can have an adverse impact on an individual's ability to make sense of their environment and may need regular monitoring.

### **• Declining vision**

Some individuals may experience declining vision. Again, indicators of declining vision may not always be evident and regular monitoring is recommended. Visual loss may be unilateral or bilateral and may accompany another medical condition such as diabetes (retinopathy).

A person with declining vision may experience new problems such as bumping into objects. They may adjust to their reduced vision by:

- Sitting closer to the television
- Increasing use of touch to identify objects
- Holding objects closer to the eyes.

The above indicators may not be relevant to a person who is profoundly deaf or blind and unable to communicate what is happening to them. In this case, people known to the affected individual such as family members or carers may be the first to notice that there are changes. In some instances though, changes may not be evident, but as the affected individual relies on whatever hearing or vision they have to make sense of

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<sup>2</sup> Munroe, S. (1999) *A Survey of Late Emerging Manifestations of Congenital Rubella in Canada*. Ontario: The Canadian Deafblind and Rubella Association.

<sup>3</sup> O'Donnell, N. (1991) *A Report on a Survey of Late Emerging Manifestations of Congenital Rubella Syndrome*. New York: Helen Keller National Center.

their environment, an annual hearing and visual assessment may be a good way of identifying problems early.

Regular monitoring of hearing and vision can help to identify any changes, and where necessary the implementation of management programmes and communication strategies.

- **Disturbances in behaviour**

Behavioural disturbances have been reported in individuals with congenital rubella, but it is not certain what may be causing this. It has been suggested that they may be due to a neurological problem, hormonal problem and problems with the eye and/or ears. Puberty may also have a role to play and environmental changes should not be forgotten as a possible factor.

It is important to note that behavioural changes may not necessarily mean that there is a medical problem. Changes in behaviour could be as a direct consequence of an individual's inability to communicate their needs, particularly where their ability to do so is limited or non-existent.

## **Where can I go for help?**

If you:

- would like to find out more about deafblindness or the services for deafblind people in your area
- require information in alternative formats including braille, large print, audio or disk - or would like this factsheet to be translated into your first language

please contact Sense's Information Team.

Telephone: 0845 127 0060

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