

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 1940/5 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 old 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 wellbeing. Monitoring should include regular medical assessment.

The increased incidence of the following conditions has been confirmed by research (1). This means that these conditions occur more frequently amongst people with congenital rubella. 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

If you, or someone you know, experience 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.

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 (2)(3). 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 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.

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.

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 more information about the delayed manifestations of rubella, you can contact Sense (publisher of this factsheet) at either of the addresses below:

Sense, The National Deafblind and Rubella Association
11-13 Clifton Terrace
Finsbury Park
London N4 3SR
England
Tel: 0044 207 272 7774
Fax: 0044 207 272 6012
Email: enquiries@sense.org.uk
Website: www.sense.org.uk

Footnotes

- (1) Logan, S and Tookey, PA. (3rd 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).
- (2) Munroe, S. (1999) *A Survey of Late Emerging Manifestations of Congenital Rubella in Canada*. Ontario: The Canadian Deafblind and Rubella Association.
- (3) O'Donnell, N. (1991) *A Report on a Survey of Late Emerging Manifestations of Congenital Rubella Syndrome*. New York: Helen Keller National Center.