



Fact Sheet

Colorado Services for Children with Combined Vision and Hearing Loss (Deafblindness)

Focus on Congenital Rubella Syndrome (CRS) By Marty Elquist, Nevada Dual Sensory Impairment Project

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What is Congenital Rubella Syndrome (CRS)? Rubella is a virus that usually causes a mild illness in children or adults; however, if a pregnant woman contracts rubella, the consequences for the unborn child can be severe. Rubella, and subsequently congenital rubella syndrome (CRS), is a vaccine preventable disease.

What causes CRS? CRS is caused when the rubella virus is passed from the mother to her developing fetus. Up to 90% of infants born to mothers who contracted Rubella during their first trimester develop CRS (Mayo Clinic, 2005; Zimmerman & Reef, 2002). CRS can vary according to the developmental stage of the fetus. Infection during the first trimester affects more developing organs than later in pregnancy; therefore the symptoms are more severe for infants who contracted the virus at an earlier gestational age.

What are the Symptoms? Rubella is characterized by a distinctive red rash, swollen glands, low-grade fever, runny eyes, sore throat and joint pain in children and adults. Rubella is generally a mild infection. Up to half of those infected with rubella do not have symptoms (Immunization Action Coalition, 2005).

In contrast to rubella, CRS is not a mild infection. Unfortunately the symptoms persist throughout life. There is not a “typical” picture of an individual with CRS; a wide-range of characteristics exist. There are two phases of medical issues: early symptoms and delayed symptoms (Parker, n.d.).

Early Symptoms:

- ❖ Hearing problems—*see following discussion,*
- ❖ Visual problems—*see following discussion,*
- ❖ Congenital heart disease,
- ❖ Mild to severe neurological problems including microcephaly
- ❖ Small stature,
- ❖ Enlargement of the liver & spleen,
- ❖ Genitourinary problems (undescended testicles,
- ❖ hernia),
- ❖ Purpura (dark purplish areas on the skin),
- ❖ Jaundice,
- ❖ Meningoencephalitis (meningitis bacterial infection combined with swelling in the brain),
- ❖ Developmental delay,
- ❖ Radiolucent bone disease (bones that allow the passage of x-rays and, therefore, are difficult to see using traditional radiology).

Delayed Symptoms:

While medical professionals are aware of early problems associated with CRS, the delayed problems are not widely known. It is important to note that most people with CRS will not develop any of the late symptoms.

- ❖ Diabetes,
- ❖ Under-active or overactive thyroid,
- ❖ Growth hormone deficiency,
- ❖ Glaucoma (disease of the optic nerve),
- ❖ Changes in seizure disorder.

(Center for Disease Control, 1999; Medicine-Net, 2006; Parker, n.d.).

What are the Implications for Hearing? Hearing impairment is the most common disability resulting from CRS. Hearing loss can range from mild to severe and can both decline, or improve in the first few years of life (Parker, n.d.).

What are the Implications for Vision? The vision of individuals with CRS can range from normal to total blindness. Some common visual abnormalities include:

- ❖ Pigmentary retinopathy (progressive vision loss),
- ❖ Cataracts (clouding of the lens) in one or both eyes,
- ❖ Retinopathy (inflammation of the retina),
- ❖ Nystagmus (uncontrollable movement of the eyes),
- ❖ Microphthalmia (one or both eyes are small).
- ❖ Optic atrophy (deterioration of the optic nerve).
- ❖ Congenital glaucoma (disease of the optic nerve that happens prior to birth resulting in large globes and clouded corneas).

What is the frequency in the U.S.? Between 1964 and 1965 there was a worldwide epidemic of rubella. In the U.S. alone, approximately 20,000 were born with CRS. Thousands of these individuals were reported to be deaf-blind (Helen Keller National Center, 2005).

Today, rubella cases are at a record low in the U.S. Only 9 cases of rubella were reported in 2004 and only 4 cases of CRS were reported from 2001-2004. Worldwide there are still an estimated 100,000 infants born annually with CRS (Centers for Disease Control, 2005).

Is there a treatment? There is a vaccination for the rubella virus that causes CRS. The mumps, measles, rubella (MMR) vaccination is *generally* given during childhood in two doses; the first between 12-15 months-old and the second between 4-6 years-old. There is not a treatment to “cure” CRS. The treatment of CRS focuses on treating associated problems if needed (e.g., cataract surgery, hearing aids, seizure medication).

Additionally, it will be determined on an individual basis whether or not special education and related services (e.g., physical therapy, occupational therapy, and speech therapy) are needed. These educational services are determined by the individuals’ needs and are intended to assist the child in receiving an appropriate education.

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