

## Rubella Network

About 25 people participated in the Rubella Network meeting at the DBI European conference in Senigallia, Italy, the morning of September 25<sup>th</sup>. This network is interested in the broad range of issues around rubella, including immunization, health, diagnosis and quality of life. It is open to anyone who is interested in this topic.

According to the World Health Organization (WHO), international immunization efforts are effectively reducing the incidence of rubella globally.

Linda Long from Scotland announced good news about the success of the MMR immunization program. A vaccine against measles, mumps and rubella was introduced into the childhood immunization program in 1998. Ninety-two percent of children in Scotland have received one dose of MMR by age 2, 95.6% by age 5. The positive outcome of high MMR uptake amongst children in Scotland is evidenced by the low incidence of rubella seen in Scottish communities and the fact that there has not been a baby born with congenital rubella (CRS) in Scotland in the 21st century. We are grateful to the many health professionals who continue to provide good information to families and support them to understand the potential consequences of infectious disease outbreaks amongst children.

Joff McGill of Sense, UK, reported that immunization rates in the UK have been severely affected by the MMR/autism debate, despite the fact that there has been no credible evidence linking the vaccine to autism. The cumulative effect of this decline in immunization is that an estimated 3 million children in the UK have not been vaccinated for MMR! Sense supports MMR vaccination as the safest way to protect children. For more info on this issue, visit the Sense website [www.sense.org.uk](http://www.sense.org.uk)

Health Factors: Susannah Barnett of Sense UK reported on a study she is conducting which will focus on the health of people with CRS. It will also gather health information on those who were exposed to rubella in utero but who were not born with health issues related to this congenital rubella infection. A second study will compare health problems of individuals with CRS and those of their siblings without CRS. The results of this study may help us to better understand the influence of a genetic predisposition to health concerns (such as diabetes) as opposed to those who develop illness or disease from CRS only.

Health Related Quality of Life of Mothers of Adults with CRS: Normadeane Armstrong reported on the results of her doctoral dissertation on this topic. It was the first time that mothers' health was studied in relation to caretaking for this population. It confirmed what moms already knew - that caring for a child with multiple needs can have a major impact on the mother's health. Hopefully, this study will lead to more research on the health of parents and caretakers and better supports for all.

Jude Nicholas and Evabritt Andreassen of Denmark are looking into many great questions:

- Do individuals with CRS have a high risk of developing dementia, especially those with intellectual disabilities?
- How do we know if cognitive decline is related to CRS or to deaf-blindness in general? Many tests that are used to test dementia in the sighted hearing population are not normed to those who are deaf-blind.
- What do we know about structural changes in the brain? We need to do individual studies or assessment to find out what's going on, possibly using siblings for comparison.
- For people with CRS, rubella is an infectious disease and the infection affected each person differently. How will assessments determine the amount of cognitive decline related to CRS? MRI can determine if there is an actual physical structural change in the brain, but this does not necessarily mean that it will have a direct effect on behavior or health.
- What is the effect of mental health issues, i.e. depression, on one's cognitive functioning?
- And finally, have we sufficiently studied the impact of excellent communication on the health status of those who are congenitally deaf-blind and aging? Stay tuned as we learn more about the results of these studies.

Nancy O'Donnell and the Helen Keller National Center (HKNC) continue to work with the Centers for Disease Control to collect blood samples for the biomarker study. They are trying to determine if there is a unique biomarker in the blood of adults with CRS and, if so, can that be used to develop a blood test to diagnose CRS in adults whose diagnosis is unknown? HKNC also continues to collect and analyze data on their 2004 survey. Results will be posted at [www.hknc.org](http://www.hknc.org)